



1990

## A Descriptive Analysis from a Kantian Perspective of Conflicts between Society and Families Relative to the Parenting of Children with Special Needs

Stephen B. Parrish  
*Loyola University Chicago*

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A DESCRIPTIVE ANALYSIS FROM A KANTIAN PERSPECTIVE OF  
CONFLICTS BETWEEN SOCIETY AND FAMILIES  
RELATIVE TO THE PARENTING OF CHILDREN WITH SPECIAL NEEDS

by

Stephen B. Parrish, M.S.Ed.

A Dissertation

Submitted to the Faculty of the Graduate School  
of Loyola University of Chicago in Partial Fulfillment  
of the Requirements for the Degree of  
Doctor of Philosophy

March

1990

## ACKNOWLEDGMENTS

The author acknowledges the attention and assistance extended to him by Dr. Walter P. Krolikowski, S.J., Director of the Dissertation Committee and Marcel Fredericks, Ph.D., Gerald Gutek, Ph.D., and Steven I. Miller, Ph.D., Committee members, in the preparation of this work.

## VITA

The author, Stephen Bryson Parrish is the son of Matthew Denwood Parrish and Virginia (Bennet) Parrish. He was born December 13, 1948, in Alexandria, Virginia.

He received his early education in the John Greenleaf Whittier Elementary School and the Paul Junior High School in Washington D.C., the Sidney Lanier Junior High School in Fairfax County, Virginia, The Frankfort American Junior Highschool and the Frankfort American Highschool in Frankfort, West Germany, and the W.T. Woodson Highschool in Fairfax County, Virginia.

He received his higher education at Ithaca College, 1967-1968, and at Brigham Young University, 1970-1973 where the Bachelor of Arts degree in German Language was conferred on him. From 1974 to 1977 he attended Central Missouri State University in Warrensburg, Missouri where he earned the degree of Master of Science in Education. This course of study was taken concurrently with service as an officer in the United States Air Force.

Upon leaving the Air Force in August of 1977, Mr. Parrish began service as Coordinator of the Birth Defects Service at Children's Memorial Hospital in Chicago where he concurrently began work on the degree of Doctor of Philosophy. In 1978 he began work at Loyola University Medical Center where he was active in clinic management, research, publication and medical conference production. In 1983 he left Loyola to work for Medical Educational Social Service Association as Executive Director. In 1989 he began work at the Chicago College of Osteopathic Medicine as Associate Director for Continuing Medical Education.

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## CHAPTER 1

### INTRODUCTION

Handicapped children, their families and society are frequently in conflict. Families and societies attempt to provide for the physical maintenance, emotional welfare, medical treatment, and education of their children whose physical, mental, or emotional disabilities demand that their special needs be met. Although both the family and society have a vested interest in preparing these children for productive participation in home and community life, the problems precipitating conflict are not easily resolved: What are the rights, duties and obligations of the family, of the child, and of society? The overlap of responsibilities and the need for cooperation and support for each other's effort is obvious. A better understanding of these rights and duties is essential in the establishment of a framework for the resolution of disputes between families and society relative to the handicapped child. This understanding can also contribute to the building of family strengths and mechanisms for providing more fully for the advancement of the child. Community institutions

will likewise benefit through the adoption of attitudes and specific programs based upon these understandings. One way to achieve an understanding of parental and societal rights and duties is to view them from a sound philosophical framework, from a perspective. What do we mean by parenting and what is special about that function when the child being parented is handicapped?

Parenting handicapped children is a labor beyond love or duty and as such must draw upon innate human strengths which maintain the will to provide and care for a child even when the parent may at times feel at a loss both to express love or to feel bound by either that love or by any sense of duty as learned in the context of cultural and societal expectations. Parenting is as diverse in its possibilities as are the families who experience it. Parenting handicapped children entails all of the vicissitudes and joys, trials and endearments of otherwise "normal" parenting, but everything is magnified, intensified, and multiplied by the physical, emotional, and intellectual abnormalities of the handicapped child. The word parenting is a relatively modern coinage and is designed to describe what passes from parents to children in the way of love, guidance, education, and physical maintenance. Its meaning encompasses duties and obligations as well as rights and privileges; responsibilities

and worries as well as joys and exhilarations. Parenting is a never-ending adventure that begins with conception and inevitably passes through many trials, but it can just as surely be a process filled with satisfying accomplishment.

Parenting is a relational process. To understand parenting one must understand the nature of being parented, or the process of growth and development of children and the effects that parental influences have on children. Childhood, implying the position of a child in the parent-child relationship, also has its rights and privileges as well as its obligations and duties and will, as surely as parenting, be an experience with both trials and joys. Child implies offspring of adults, but one must keep in mind that children are also born of children. Child is also an ageless state like that of "parent". Although society looks upon maturation as the growth from childhood into adulthood, parents tend to see their children through all the years of growth as still their children. Some children, because of their defects, may remain as children mentally, emotionally and socially, all of their lives. Some parents may seem to become as children emotionally or mentally because of mental illness. When otherwise normal parents become very old they may require physical care and/or emotional support not unlike what parents provide for small

children, and so the "parent" and "child" roles may reverse.

This work will deal specifically with the parenting of the handicapped child and will address the conflicts which may arise between parents and those outside the home with regard to the parenting of the child. A theoretical framework based upon a Kantian perspective will be developed in order that the issues of rights and obligations of parents, society, and children may be addressed. Although cases will be cited and examples which illustrate various situations of conflict will be recounted, it is not the technical solution of specific problems, but rather a theoretical basis for decision-making that is sought.

Two categories of rights and obligations will be considered, those "natural" and those "legal" on the part of each of the subjects, i.e., parents, children, and society. The resultant social philosophy is not designed as legal theory and does not address many legal questions which arise in the various legal systems of states and nations. It is presented rather as an approach to familial and societal living with respect to the particular issues that handicapped children bring to the attention of those who are responsible for their care, education and welfare.

The conflicts between the family and society relative to the rearing of children with special needs concern everyone, whether as a potential parent, a potential taxpayer, or a potential caregiver. All human beings partake of the parenting process because the outcome affects everyone. The process itself demands the involvement of a community of people. There is a relationship between the parent and the taxpayer because the taxpayer may have to pay for the failures of parenting. Each child is a potential taxpayer or a potential consumer of revenue. The ratio of children to adults in a society affects its economy. Everyone has an interest in the family process and everyone is related in that process because it is the means by which human life regenerates itself.

This work will address the issues of concern to each interest. When a child is born with an abnormality, or when later in a child's development an abnormality is evident, questions arise in the minds of parents and society. Could the condition have been prevented? When it does occur, can it be alleviated by early intervention? Is the condition contagious? Will the child grow and reproduce and possibly pass on the problem to future offspring? What is the risk to the parents of having a second child with the same condition? Can a recurrence be prevented? Was there something in the environment which contributed to the

etiology of the defect? Can this teratogen be eliminated? If genetically defective children reproduce, will this "pollute the gene pool?" What will be the cost to the family and to society for the rearing, education, training or long-term care of the child? Who will pay the cost?

Each party to the parenting process, parents, children and society, has an interest in these questions. Each has a perspective based upon how these concerns affect them. How each party deals with the concerns will also reflect the relationship it has to the other two parties. Each is concerned with its capacity to cope with the problem, the cost to each, the prevention of the problem, or the overcoming of the problem. In a deeper psychological context which affects how each of the foregoing questions is addressed, each party is subconsciously groping with the identity crisis precipitated by the presence of the abnormality. The child with the defect is naturally concerned about his own identity and where he will fit into society, given his abnormalities. The siblings reflect on the presence in their family of something different from what they see in other families and on how others perceive them in light of this abnormality. Communities may be compassionate when a defect occurs among them, or they may be offended and try to expel the family out of fear or ignorance, thinking that they might themselves in some way

become tainted. This societal behavior in turn has an effect in turn upon every member of the family, not only physically, but emotionally as well.

Because of the importance of every member of society as a contributor and as a receiver of the benefits of human association it is imperative to establish the rights, duties, and obligations that each has relative to the others. In the specific case of the handicapped child and his family it is imperative to establish what the rights, duties and obligations of society, the child and the family are. There is clearly no consensus in the world today with regard to these issues. It is therefore proposed that what has been written regarding these issues should be examined and the conflicts which appear to exist should be analyzed from the viewpoint of seeking a resolution to them.

Through an examination of selected literature addressing conflicts between parents and society with regard to the rearing of handicapped children fundamental questions which delineate the concerns of each party will become evident. It will be necessary to examine writings in philosophy, psychology, sociology, medicine, bioethics, education and law (comprising examples from case law and public policy) as well as expressions from the lay public relative to the conflicts between parents and society concerning the parenting of handicapped children.

After the presentation of these conflicts, selected principles from Immanuel Kant's Fundamental Principles of the Metaphysic of Morals<sup>1</sup> which have specific relevance to basic rights and obligations will be discussed. A philosophical perspective of the family will be offered in order to provide an interpretation of the roles of parents, children, and society and their necessary relationship to one another. With the aid of the principles offered by Kant, some fundamental considerations will be expressed as possible guidelines in the formulation of policies for society and for the home.

Given the multidisciplinary nature of this work, it is advisable to define terms which are central to the discussion.

Child: all human beings are children and as such have a relationship to parents. They may not know who their natural parents are. They may have grown up in an institution. Nonetheless, they have a concept of what constitutes a parent, and they will have known some influence or guidance of a parental nature. We more specifically define children as those people who are still under the jurisdiction, control or tutelage of parents or of those functioning as parents. The parent-child relationship does not terminate at a specific age, nor upon the child's leaving the home. Some of the rights, duties and

obligations of children, parents and society may change at particular milestones in human development and upon separation.

Parent: Biological parents, adoptive parents, institutional surrogate parents, in some cases relatives who function as parents--all may be considered parents. There are legal definitions of the responsible parental guardian, and accountabilities before the law will depend upon the legal definition. All adults who come in contact with children will bear some parental aspect in their example, for better or for worse. In general, the term parent in this work will apply to the legal guardian of the child. Any exceptions to this definition of parent will be noted and clarified.

Conflict: Any situation presenting a struggle between two or more parties. The conflict may not necessarily be perceived by all parties. For example, a poor woman may repeatedly have illegitimate children in spite of a high risk environment or the handicaps of her other children or a high risk for recurrence of a defect, and she may be perfectly content to continue in her course because of increased welfare benefits from the state. She does not perceive the conflict, but society may strongly object to supporting her practice. The woman may be oblivious to any need to defend her practice. There is nonetheless a

conflict between society and what it perceives as an undesirable situation.

Parenting: The process of conceiving, bearing, nurturing, guiding, educating, disciplining and relating to children. In general the parenting process includes responsibilities prior to conception, prenatally, and throughout the life of the child, but most especially during the time the child is in the home or under the direct guardianship of the parent who is meeting physical, emotional, intellectual, social, and spiritual needs. The basic element of parenting is the provision of shelter, nutrition, love, social guidance, and education.

Handicap: Any condition, be it physical or psychological, genetic or acquired, which renders the individual in need of special consideration for purposes of education, community access, vocation, or social relations constitutes a handicap.

Society: All individuals, groups, or governmental bodies outside of the home. The home is nonetheless a part of society within which there may be a functional inner society known as the family. This society includes siblings and other relatives or individuals living in the home. The familial society may extend beyond the walls of the home to the homes of other relatives who are a part of the extended family relationship and have, by virtue of their kinship

through blood or marriage, a special interest in the family beyond what the rest of society would have.

The Law: This must be defined in several categories.

1. Those laws and regulations which are statutory and which directly govern the affairs of society.
2. Those guidelines that families may decide they wish to accept as necessary for the governance of the home.
3. Societal mores which influence the way in which people relate to one another and which may also influence the judicial interpretation of statutory law.
4. Those guidelines which are considered acceptable professional practice by a particular professional body, i.e. medical, educational, psychological, legal, social work, etc.
5. Those natural and universal laws of human existence the violation of which is disadvantageous to individuals and society.
6. Those religious laws which individuals, families or communities may accept as valid and which may influence their actions, interpretation of events or circumstances, and self image. These laws will vary from individual to individual, family to family, and community to community, and varying

degrees of faith in them will be evident. They may, however, have a high degree of influence upon the reactions of individuals or groups to such things as handicaps ("Who sinned, the man or his parents?")<sup>2</sup> and upon parental accountabilities.

A word of caution to the readers of this work: It deals with many controversial subjects. Some of the concerns reflected are deeply rooted in the nature of human existence and derive from cultural and societal mores as well as individual and group beliefs which are dear to those who hold them. Case presentations are textual and discussions expound a variety of views. Some appear as highly authoritative and are supported by sound research. Some are highly opinionated and reflect traditional and non-traditional belief systems. No one reading this work should conclude that the author subscribes to any of the positions taken unless they are specifically detailed as the author's position. There should also be no conclusion by, nor any offence to any individual or group because of any association of circumstances. For example, a detailed description of a family with a handicapped child which is also in poverty or of a particular race should not suggest that there is any necessary correlation between the condition of the child, the race, or the socio-economic status. If valid statistics should be cited to indicate a

correlation, then some conclusion might be in order. Because the literature reviewed in this work is selected for the purpose of elucidating specific areas of conflict it does not necessarily represent the total picture of any of the situations dealt with. Some of the literature, in spite of highly recognized and authoritative sources, well-documented research and valid statistics, nonetheless betray the authors' bias concerning cultures, handicaps, races and gender. These works are especially valuable because they help in the endeavor to understand the roots of much of the conflict being discussed if only they are viewed with a critical eye. Some works may appear to reflect bias where no bias exists, but rather the facts may be offensive to those who feel addressed. The reader should proceed with an open mind and be prepared to see through unsound arguments and the reader's own biases.

## CHAPTER 2

### A REVIEW OF THE LITERATURE

The literature which addresses the concerns of handicapped children and their families often takes into account the conflicts and the potential for conflicts between society and families rearing children with handicaps. The literature which addresses issues of familial and societal rights and duties in relation to children in general may also have significant implications in matters of concern to the special populations examined in this work in several ways. First, handicapped children are, like all children, persons under the law and have an equal right to the benefits of the law. Second, all children have the potential to become handicapped and all people capable of bearing or adopting children are potential parents of handicapped children. Children who are impaired or disabled constitute at least ten percent of all American children and whatever is done in schools, hospitals and social service agencies has an effect upon them. Disabled children also constitute a "minority group" and as such are affected by laws and social attitudes that

are directed toward minorities. Many of the problems faced by handicapped children and their families are not directly related to the handicapping conditions of the children, but are rather the result of the fears, prejudices and attitudes of other members of society. This negative outlook is potentially a source of conflict, and it is the subject of a collection of literature of significance to this work.

In order to limit the extent of this review and still adequately represent the main components of the subject, literature will be examined from five areas: psychosocial, educational, sociolegal, philosophical and parental. There will be an overlap of the concerns addressed in these areas because each field has components of the other four. This approach will provide a selective review of works from the recent past which will give the reader sufficient information to understand the basic issues and concerns at the root of conflicts between society and families with handicapped children.

### Psycho-Social Literature

Parents of handicapped infants evince an emotional sequence of disappointment, denial, anger, and guilt. This

sequence sets the stage for conflicts between families and society according to Holt, Legeay and Keogh, Klaus and Kennell, and Marion.<sup>3,4,5,6</sup>

In 1975, Drotar, et al. described a series of stages that parents pass through in adapting to the birth of a handicapped infant: shock, denial, anger, sadness or anxiety, and finally, adaptation. According to Canning and Pueschel, handicapped infants violate parental expectations of rearing a normal, well-functioning child. Because interaction patterns between parents and infants are more problematic as a result of the limited abilities of the handicapped infants, there is a pattern of reduced responsiveness during social interchanges. This is confirmed in studies by Vietze et al., Rutter, Tallman, and Parke<sup>7,8,9,10</sup> Chronically handicapped children impose long-term and continuing care-giving demands which may ultimately necessitate institutionalization. There is almost always an escalating anxiety about the cost of providing for the child. According to Gumz and Gubrim, fathers in particular are more concerned about future problems such as economic and social dependence and legal and educational issues than are the fathers of non-handicapped children.<sup>11</sup> This is also confirmed by the work of Meyer et. al.<sup>12</sup> Gumz and Gubrim find that the nature of concern evinced varies according to the sex of the parent.

Fathers voice instrumental concerns, especially cost issues and the ability of the child to be self-supporting. Mothers, on the other hand, experience an explicit crisis and indicate concern about the emotional stress of caring for a handicapped child.<sup>11</sup>

How parents adapt to the stressful event of the birth of a handicapped child may depend upon how they perceive the event and to what they might attribute the cause of the defect. The course of adaptation is explored by Afflect, Allen, McGrade, and McQueeney.<sup>13</sup> They find that what the mothers of infants with severe perinatal complications believe to be the cause of the infants' medical problems affects their mood and their expectation of what caregiving-related difficulties they might anticipate. How a mother views the cause of her child's defect strongly influences her approach to the care of the child. Some mothers speculate that their children's defects might have been caused by something they themselves did (e.g., sex during pregnancy, excessive exertion, smoking). Others speculate that someone else did or did not do something (e.g., obstetric error, insufficient stimulation in the intensive care unit) or chance ("just one of those things that happen"). Those who blame themselves for their infants' problems report a stronger conviction that their infants' recovery and future condition are dependent on

their own actions and that similar problems might be prevented in future deliveries. Others who attribute a greater role to chance report less personal control over their infants' recovery and over prevention of similar problems in the future. Blaming others seems to be unrelated to controlled cognitions. According to Tennen, Affleck, and Mershmen,<sup>14</sup> a greater perceived severity produces greater self-blame, which in turn plays an indirect role in emotional adaptation through its association with the belief that a recurrence of the negative event might be prevented. Tennen, et al. suggest that self blame may have a "potential healing role for some victims of adverse life events."

Parents may derive their perceptions of a handicapping condition from their own rearing, and this will then affect how they will approach their own children.

The stress of having an infant with a handicap sets the stage for conflict with those outside the family who play a role in caring for that child.<sup>12</sup> The birth of a handicapped child may also set the stage for conflict between mothers and fathers. According to research by Holt and Meyer, in spite of the increased need created by the birth of a handicapped infant, fathers of retarded infants and children do not show an increased participation in child care.<sup>3,15</sup> In fact, the extent to which fathers of

retarded children participate in care-giving activities is less than might be expected. Stoneman, Brodey, and Abbott<sup>16</sup> find that mothers assume the role of teacher more frequently in a structured interaction situation than do fathers when there is a handicapped infant in the family.<sup>10</sup> But mothers and fathers do not differ in the extent of their teaching in families of non-handicapped children. A more recent study by Bristol and Gallagher<sup>17</sup> shows that both mothers and fathers report that fathers assume less responsibility for total tasks in families of developmentally disabled children than do fathers in families of non-handicapped children. Nonetheless, father assistance with non-handicapped siblings does not differ with cross-family types.

Michael Lamb<sup>18</sup> suggests that diminished father participation reflects the fact that fathers derive less satisfaction from retarded than from normal children and that paternal response--unlike maternal response--is discretionary. The maternal role is defined in such a way that fathers may increase or decrease their participation, depending upon their preferences and satisfactions, whereas mothers are traditionally expected to be equally committed to all of their children--regardless of personal preferences or the individual characteristics of their children. A number of studies demonstrate that spousal

support is an important correlative of both parental competence and infant development. Trause and Kramer,<sup>19</sup> in an interview study of parents of pre-term and full-term infants, find that maternal adjustment difficulty is related inversely to father sensitivity to their spouses' needs and feelings. As does the birth of a pre-term infant, the birth of a handicapped infant often has a negative impact on a marital relationship. A number of investigators find extensive marital and familial conflict is a result of the birth of a retarded or handicapped child. Holt, Lonsdale, Tew, et al.<sup>3,20,21</sup> find that mothers of developmentally disabled children report less satisfactory marital adjustment than mothers of non-handicapped children. However, Tew et al. find that the fathers of the two groups do not differ and speculate that dissatisfaction may in part be mediated by the lower level of expressive support--emotional, intellectual, and recreational--that the mothers of developmentally disabled children perceive that they receive from their husbands. Among United States parents of children five years old or less, divorce or separation rates for parents of handicapped children are nearly twice as high as are divorce or separation rates for parents of normal children. Rates are highest among families with low income and low education levels; however, as Bristol comments:

...separation and divorce are seldom due entirely to the stress of the handicapped child. It appears that marital breakdown is most likely to occur in families which are experiencing personal or financial difficulty before the birth of the child, and those in which the child was conceived premaritally, and those in which the care of the defective child is not a shared value, or in those where the demands of the handicapped child outstrip the available resources,<sup>19</sup> of the family and the services found in the community.

Tew, et al. find that in England parents of spina bifida infants were divorced nine times more often than were their age counterparts, assessed ten to twelve years after delivery, while couples whose spina bifida infants were stillborn had divorce rates three times as high as their age counterpart.<sup>18</sup> Tew also reports that divorced fathers are likely to remarry, while their ex-wives, who usually retain custody of the handicapped child, do not. It is clear that women in particular assume a disproportionate share of the burden. They feel ultimately responsible for the child, whereas the fathers believe that they have a choice.

Families do not exist as units independent of other social organizations within society. Thus, families need to be viewed within their social context and a recognition of the role of the community as a modifier of family modes of interaction is necessary for an adequate understanding of the process of parenting a handicapped child. According to Holt, society plays a significant role in modulating

interaction patterns in families of handicapped children. An appreciation of the problems associated with the care of these types of children is necessary in order for society to relate appropriately to the family.<sup>3</sup>

There are generally two kinds of support systems which operate to alleviate the difficulties of rearing a handicapped child: those which are formal, such as health-care facilities, social service agencies, and recreational facilities; and those which are informal, such as extended families, neighbors and co-workers.<sup>22</sup> But where these extra-familial systems are inadequate or are reflective of prejudice and ignorance which do not allow appropriate support, conflicts may arise between families and these institutions. In some cases, no matter how adequate the support systems are, the families will have difficulty accepting their help, and conflicts may arise.<sup>21</sup>

A longitudinal project by Parke and Tinsley revealed a number of differences in the patterns of social-support utilization among families of handicapped and normal children.<sup>23</sup> At regular intervals parents completed a social support questionnaire which recorded the extent to which families used either informal or formal support agents. The researchers recorded the parents' stated reasons for utilizing each of the support services, that is, whether it was for social, emotional, informational, or physical

assistance. They found marked differences between maternal and paternal utilization of support services. As other studies have also revealed, these questionnaires showed that mothers visit and phone relatives and friends more often than fathers do. The mothers made more contacts with informal networks than fathers did, for information purposes or for assistance with home baby care, for alleviating worry or consternation about their babies, and for relaxation and enjoyment. In general, mothers utilized informal networks more than fathers did. It was reported that parents of handicapped children seek information more often from professional or social service agencies than do parents of normal children. This finding was qualified by the fact that the fathers of handicapped children sought information from formal support agencies more often than did fathers of normal children during hospitalizations. Mothers, however, did not differ. Mothers of handicapped children did not differ from mothers of normal children in their contact with support services. Social networks are particularly important sources of assistance to families trying to cope with and adapt to handicapped infants and children.<sup>24</sup> However, a number of studies have documented that these families are socially isolated. One study by McDowell and Gabel found significantly inadequate social networks for parents of mentally retarded infants as com-

pared to the social networks available to a contrasting group of parents of normally developing infants.<sup>25</sup> The inadequacy was attributable to smaller extended kinship networks. There were many reasons given for this isolation. First, the families were found to be too emotionally and physically exhausted to maintain ties with friends and relatives because of the heavy care-giving demands placed on parents by a handicapped infant. This burden restricted the amount of time available to spend with friends and relatives. Second, the assumed stigma of a retarded child in the family led parents to avoid outside social contacts. Third, outsiders may have ostracized the family of the retarded person they could neither accept nor understand.

Relatives, and even grandparents, may be less capable of providing emotional support when a retarded or handicapped infant is born, partly because of their own consternation and grief on learning that their own grandchild is handicapped. Grandparents may themselves need support and may become an additional burden for the parents. Also, many potential social support agencies in the informal network, such as friends or relatives, may be less capable of providing assistance and care for the handicapped child because specialized arrangements for these kinds of children are required.<sup>26</sup>

The hospital is first among formal support systems for families of handicapped children although there are many other facilities offering intervention programs for retarded and handicapped infants and children. According to Pascoe, few of these programs are family-oriented but focus instead on the mother. Many programs designed for parents are functionally mother programs, because they are often held at times inconvenient for fathers, and they tend to address mothers' concerns.<sup>27</sup> Thus, it is not surprising that father participation in these programs is very limited. According to Meyer, Vadasy, Fewell, and Schell,<sup>12</sup> fathers have difficulty in adjusting to and accepting the birth of a retarded, handicapped child, and it is, therefore, important to include fathers in intervention efforts. Few programs designed to offer supportive services to parents and specifically to fathers, have been developed, and the capability of formal institutions to deal with the stresses that families with handicapped children suffer is limited. The stage for conflicts with families is thus set.<sup>28</sup>

Advances in medical technology over the past two decades have significantly enhanced our ability to detect fetal abnormalities at an early stage of development. According to Phillip, psychological evaluation of the impact of these diagnostic screening programs on families

has not kept pace with medical advances in the detection of them.<sup>29</sup> Much more needs to be learned about the impact of early screening on maternal and family adaptation during pregnancy and about ways to decrease the negative emotional side effect of early detection as well as to increase ways of assisting families to cope more effectively with the prospect of giving birth to an infant at risk for retardation, impairment, or physical defect.

According to Affleck, Allen, McGrade and McQueeney, we need to learn more about what determines parental attitudes toward those they deem medically responsible for the development of the fetus and what expectations of the infallibility of physicians parents have.<sup>13</sup> Parents who blame medical experts for the less than normal condition of their newborns are hampered from the beginning in their effort to adapt to their child's affliction. Modification of parental attributions of blame by means of education in both the pre-natal and post-natal periods might help parents to adapt to their child's handicap more adequately. Families are changing in that they are able to deal with abnormality. According to Polkowitz, in the last two decades, mothers and fathers have redefined their family roles.<sup>25</sup> Shifts in sex role, etiology, work patterns for men and women, and age and timing of parenthood have combined to alter the social atmosphere in which men and

women undergo the transition to parenthood. How fathers and mothers react to the birth of a handicapped child has also changed, and is strongly influenced by societal opinion.<sup>30</sup> According to Bloom-Feshbach, the use of social network agents outside the nuclear family is negatively correlated with the fathers' participation in child care. The pattern of isolated family units separated by great distances from blood relations that is characteristic of contemporary life in America may be responsible for greater participation by fathers. Several social trends, then, have converged to create conditions which have influenced fathers to participate to a greater extent in care-giving activities.<sup>31</sup>

Studies contrasting the relative influence of home and school on childrens' intellectual and educational achievements strongly suggest that the influence of the home is comparatively greater in the early years.<sup>32,33,34</sup> Children who come from homes where the parents take an active interest in the child's education tend to have higher school achievement. These studies have been for the most part carried out with normal children, but there is evidence that the relationship between parental interest in education and the child's achievement in school is likely to be even more marked when the children are handicapped. Parents need to be made aware of the precise teaching

methods and strategies used by teachers and other professionals to achieve particular teaching goals. For example, it is important that the parents and the teachers adopt consistent approaches to helping a child learn to feed and dress himself, and in encouraging him to use longer sentences or in dealing with behavioral difficulties.<sup>32</sup> Such new methods need to be discussed and agreed upon by teachers and parents so that at the very least each is aware of the approach being taken by the other.<sup>35</sup>

In spite of the fact that a growing number of studies and editorial comments from professional educators emphasize parental participation in their children's educational process, the literature discussing parental attitudes continues to record parental anxiety and frustration in dealing with professionals engaged in the education of handicapped children. According to Braunfrenbrenner and Cantrell, it is now recognized that the education of handicapped children has to be seen in a broader context than that of the schools alone.<sup>36,37</sup> This conclusion contrasts with the traditional approach in which the individual child is the main focus of attention. More recent recommendations emphasize that education in the broad sense must encompass the whole range of

environmental contexts that influence the child's development.<sup>37</sup>

Psychologists see the psychosocial costs of disability as the root cause of many conflicts between families and society. A child with continuing problems places stresses on a family which may result in pathological responses from other family members and limitations on family lifestyles.<sup>38</sup> Some of these stresses are a result of economic costs, others are not. The need to earn more money to cover the cost of a child's disability or the need to limit a family's size because of these costs can have a detrimental effect on family relationships. Other psychosocial costs, however, stem from non-economic societal reactions to disability, which are stigmatizing and victim-blaming.<sup>39</sup> Much of the early literature on disability emphasized these negative effects without noting any of the more positive aspects of life for the disabled child. Indeed, more recent studies have shown that a disabled child may also have a positive effect on family integration and the mental health of other family members.<sup>40</sup> One of the most pervasive psychosocial difficulties secondary to having a child with a disability is the sadness and desolation of parents because their child is not "normal." This acute grief reaction by parents to the birth of a disabled child may be short-lived.

Olschansky has argued that parents continue to experience "chronic sorrow" for the rest of their lives.<sup>41</sup> Although this may not have a major impact on the family's lifestyle or their love for the disabled child, its cumulative emotional cost to parents may be great.

Because of the extra attention required by a disabled child, siblings may receive less attention from their parents than they require. The disabled child's medical expenses may also leave less in the family budget for siblings' needs.<sup>41</sup> Some of the other common costs to siblings of having a disabled brother or sister include unrealistically high parental expectations, extra responsibilities at home, and fears related to their sibling's disabilities.<sup>42</sup> There is some disagreement among professionals over these effects. Powell and Ogle contend that siblings can be significantly adversely affected.<sup>43</sup> On the other hand, McMichael and Shipper have indicated that siblings are not necessarily adversely affected by the presence of a brother or a sister with a disability, and many, in fact, may benefit from the experience.<sup>44,45</sup>

Neugarten noted in his classic study of American attitudes toward disability that stigmatization predominates.<sup>46</sup> Those who act differently or appear to be different are likely to be shunned or to encounter only pseudo-acceptance by "normals." Parents and other family

members of the disabled are also likely to bear "courtesy stigma" that limits their possibilities for full social participation.<sup>46,47</sup>

Professional reactions to parents of children with disabilities often take the form of victim-blaming. When parents seek help for their children's problems, they are often treated as though they, and not their children, were the patients or clients. Parents who seek a second medical opinion, for example, are commonly labeled as poorly-adjusted or unable to accept their child's condition.<sup>48</sup> In the victim-blaming perspective, parental help-seeking is believed to derive from the parents' guilt for having given birth to a defective child rather than from a real need based on a lack of societal resources.<sup>49</sup> A second attitude that is sometimes encountered by parents seeking help is professional dominance, which prevents the parents from being in control of their own child's care.<sup>50</sup> This pattern is extensively outlined by Darling. The first psycho-social "cost" of victim-blaming and professional dominance that parents face, Darling calls anomie, or a sense of meaninglessness and powerlessness created by professionals reluctant to provide diagnostic and prognostic information.<sup>51</sup> Not knowing what is wrong with their child or how their child's disability will affect his future functioning is usually very stressful to parents. Lack of

information can lead to lengthy parental quests through a multitude of lay and professional sources. Negative encounters with professionals often continue throughout the childhood period. After they have obtained satisfactory medical care for the child, parents may have to fight for an appropriate educational placement or, later, for vocational services. This continuing quest for services is likely to be time-consuming, difficult, and stressful for parents.

Another source of conflict between families and professionals stems from advances in medical technology. Health care has developed to the point where we no longer ask, "Can we provide treatment?" but rather, "Should we provide treatment?" Before scientific developments brought treatment capabilities to the present level, we were not faced with the issue of deciding who should receive treatment. According to Polier, professionals exercise "all but unchecked discretion in determining to whom services shall be given, and from whom they shall be withheld."<sup>52</sup> According to Mearig, the individual professional ultimately controls the quality of services rendered.<sup>53</sup>

## Legal Literature: Children's Rights

There is no consensus in the legal literature as to what precisely the rights of children are. Foster and Freed see children as persons and declare that the status of minority should be done away with.<sup>54</sup> They feel that children should be legally liberated in the same sense that slaves and married women have been emancipated. According to Forer, paternalism is detrimental to the welfare of children because it impairs the ability of those having authority over children to recognize and express children's needs.<sup>55</sup> Because of the need to ensure children's welfare in spite of their parents' failures, Foster and Freed as well as James are advocating a stronger establishment of children's rights and their right to legal representation.<sup>54,56</sup> The most famous landmark case establishing a child's right to representation is that of In re Gault.<sup>57</sup> Subsequent to this case, courts have generally agreed that children have the right to due process and that their rights cannot be abridged simply because they are in a juvenile system. Thus, there should be checks upon the arbitrary exercise of either parental or public authority, and children's welfare should no longer

be regulated by gratuitous assumptions. According to Allen, the parens patriae power is not a blank check.<sup>58</sup> The most extensive intrusion of government into family life has been, according to Professor Sanford N. Katz, with reference to the parent-child relationship, and this intrusion is most often seen in poor families.<sup>59</sup> According to Rubin, government is now more frequently challenged to examine the consequences of state intervention and consider instead the maintenance of the family's status quo.<sup>60</sup> Some of the basic rights of children described in legal literature include the right to receive parental love and affection, discipline and guidance, and to grow to maturity in a home environment which enables the child to develop into a mature and responsible adult, to be supported, maintained, and educated to the best of parental ability. In return the child has a moral duty to honor his father and mother. He should be regarded as a person within the family, at school and before the law. He should receive fair treatment from all in authority, be heard and listened to, earn and keep his earnings, seek and obtain medical care and treatment and counseling.<sup>61</sup> The legal literature also discusses the importance of emancipation from the parent-child relationship when the relationship has broken down and the child has left home to escape abuse, neglect, serious family conflict, or for other sufficient cause, and

when his best interests would be served by the termination of parental authority.<sup>62</sup> Other rights expressed include freedom from legally imposed disabling or incapacitating restrictions except where it can be convincingly shown that such restrictions are necessary for the protection and best interests of the child. He is entitled to the right to receive special care, consideration, and protection in the administration of law or justice in order that his best interests may remain paramount. Watson has provided an extensive documentation of the need of a child for parental love.<sup>65</sup> The difficulties attending presumption of parental love are delineated by Foster and Freed.<sup>63</sup> According to Lewis and Mass and Engler, in order to abridge parental rights, there must be reasonable alternatives to parental authority. The lack of assurance that placement outside the home would be any better for an unhappy child may preclude termination of parental custody solely on the basis of emotional abuse.<sup>62,64</sup> With reference to the parents' right to give and the child's right to receive discipline and guidance, there is a great deal of subjectivity and latitude which leaves difficult decisions up to the courts or caseworkers. Methods of discipline differ, and parents tend to repeat those that they were subjected to in their own youth. More recent decisions have limited the parental privilege of corporal punishment and have commented on its

necessity as well as its excess.<sup>61</sup> The concept of parental love is generally defined as the affectionate relationship between those who stand in the positions of parent and child. This does not necessarily mean biological parents and child. It may mean those who have such a psychological relationship. This ongoing, nurturing care and attention not of biological kinship defines real mother love as distinguished from fantasy. Courts have supported the priority of foster parents when they are preferred and if they should choose to petition for adoption. According to Foster, the mother should not be permitted to belatedly revoke her formal surrender for adoption once the child is in a loving home and bonds of attachment have developed.<sup>63</sup>

The child's right to support, maintenance and education are usually defined in terms of parental duty. English legal literature enumerates three duties owed by parents to a child: to provide maintenance, protection, and education. Nonetheless, these duties are not enforced by effective legal sanctions. Today, most states can enforce the obligation of child support through criminal and civil actions. According to Krause, illegitimate children now have most of the same rights accorded to legitimate children. The child's right to be regarded as a person is basic to the other rights which follow.<sup>61</sup> A great deal of the difficulty parents have with minors is caused by the

refusal to accept them as individuals with their own needs, interests, and desires. Children may become scapegoats for frustrated adults who relieve their own sense of inferiority by treating children as things. To fail to treat a minor as a person in home, at school, or before the law is to deny his humanity. Thoughtful adults will presumably accept fairness as a general principle. According to Forer, fair treatment is a legal essential for children.<sup>55</sup> This was established clearly in the Gault case. According to Midonick, the essentials of fairness must necessarily be observed throughout the process of juvenile justice, and juveniles must be treated as people. It would be unfair to deny a youth his right against self-incrimination, the right to notice, the right to counsel, the right to confrontation, and other rights guaranteed by the Constitution simply on the theory that he is receiving help in a juvenile system rather than punishment.<sup>66</sup> Such were the issues in the Gault case.

## Literature of the Philosophical Perspective

The most basic issue discussed in philosophical literature which touches upon conflicts between families and society relative to the rearing of handicapped children is the basic principle of "childhood", that is, what kind of "person" a child is.<sup>67</sup> In general, philosophers have debated what kind of beings can be accorded what kinds of rights. Adults may behave in a certain way towards children with the intention of benefiting them through a paternalistic approach based upon the assumption that the differences between children and adults require that approach. Some would question whether or not the paternalistic approach is justified simply because children are less capable than adults.<sup>68,69,70</sup> Bernard Gert and Charles Culver discuss paternalism and define it as: "A is acting paternalistically toward S if and only if A's behavior (correctly) indicates that A believes that: 1) his action is for S's good, 2) he is qualified to act on S's behalf, and 3) his action involves violating a moral rule or doing that which will require him to do so with regard to S. 4) he is justified in acting on S's behalf independently of S's past, present or immediate forthcoming (free,

informed consent). 5) S believes (perhaps) falsely that he (S) generally knows what is for his own good."<sup>71</sup> Gert and Culver remarked, "We can be paternalistic only toward those whom we regard as believing themselves to be capable of acting on their own behalf."<sup>72</sup> These authors conclude that those who appear to be acting paternalistically generally do not believe they are acting paternalistically at all, simply because they do not believe that those towards whom they act paternalistically are capable of thinking, at least initially, about what is in their best interest. This attitude is in concert with the expressions of John Locke:

The power, then, that parents have over their children arises from that duty which has been encumbered upon them--to take care of their offspring during their imperfect state of childhood. To inform the mind and govern the actions of their yet ignorant non-age until reason shall take its place and ease them of that trouble is <sup>73</sup> what the children want and the parents are bound to.

The determination that children are in need of paternal guidance may be based upon two assumptions. First, that they lack moral responsibility (a person may be described as morally responsible if and only if he or she is rational or capable of being rational; and second, the factual claim that children are not rational.

To associate being rational with being moral has roots in the Kantian tradition of ethics. John Rawls, for example, has followed that perspective and combined it with Piaget's three specific successive stages of moral development, the first being morality of authority, the second being morality of association, and the third being the morality of principles. The stage of morality of principles is the only stage in which, according to Rawls, a person has a true "sense of justice," the only stage in which he or she is acting on rational principles, and thus children cannot be held morally responsible until they reach an age at which they can reason and act rationally, or rationally determine on what principles they ought to act.<sup>74</sup> In this perspective is included the concept that the child is developing into a normal human adult and a state that, according to Hamlyn, "ought to be reached."<sup>75</sup> Toulmin finds this attitude vague and intuitive and further states:

Our choice of 'stages' in psychology will be at least as value loaded as the same choice in developmental physiology; it commits us to some general view about the capacities which it is desirable for adolescents to develop--and so to an ethical opinion about the 'true' nature of man.<sup>76</sup>

According to Rawls, "while individuals presumably have varying capacities for a sense of justice, this fact is not reason for depriving those with a lesser capacity for a for

a sense of justice of the full protection of justice."<sup>74</sup>  
Thus, the handicapped become equal partakers of the just rights in society.

Philosophy Professor Joel Feinberg categorizes rights into three groups--those which are common to adults, those which are common to children, and those which are common to children and adults.<sup>77</sup> For example, the right to vote, to imbibe, to stay out all night, and so on, would be the exclusive rights of adults. These are protected liberties of choice that could hardly apply to small children. Children's exclusive rights are characteristic of children's needs and are such things as dependency rights. This would also apply to adults if they were handicapped or incapable of supporting themselves and, therefore in need of being treated as children all of their lives. Professor Feinberg then describes "rights in trust." These are rights which children have, as do adults. Adults, however, must exercise them on behalf of a child. It is then the child's right to have these future options kept open to him so that he might exercise them fully when he is more advanced and capable of making decisions about them. These are 'anticipatory autonomy rights'.

In the context of future rights of the child, a moral perplexity or a moral dilemma could arise, when those rights which are exclusively children's rights in trust are

in conflict with the rights of parents, which are adult rights, and the courts must decide. For example, there may be a conflict between the child's personal interests in growth and development rather than his immediate health or welfare, and the parents' right to control their child's upbringing, free from outside interference.

Society as a whole, represented by the state, may have an interest in the conflict between the future rights of the child and the present right of the parent to control the child. If, for example, the child were a source of infection to others, the state would become an active participant in the conflict. Proceedings against parents charged with neglect, criminal trials for violation of compulsory school attendance laws, custody hearings, or court proceedings because of a violation of child labor statutes may all become contests between the rights of parents, children, and the state, or the collective interests of society.<sup>78</sup>

Because children cannot be expected to defend their own future interests against infringements by parents, this task must be performed for them, usually by the state in its role as parens patriae. In American government, the 'sovereign power of guardianship' over minors and other legally incompetent persons has been traditionally held by the state. Mentally retarded adults, for example, are

expected to receive psychiatric care under this doctrine. Here it is the society's function to "decide for a man as we assume he would decide for himself if he were of sound mind."<sup>79</sup>

To presume to know what children would choose when they are adults creates difficult problems for courts. Generally, courts do not speak in the name of a future adult, but there are sometimes ways of inferring, or interfering with parents, so as to postpone the making of serious and final commitments until such time as the child in question is capable of making those decisions himself. In the decision of the case Prince v. Massachusetts, the U.S. Supreme Court reviewed the parens patriae doctrine:

...parents may be free to become martyrs themselves. But it does not follow that they are free in identical circumstances to make martyrs of their children before they have reached the age of full and legal discretion<sup>80</sup>, when they can make that decision for themselves.

The limits of the parens patriae doctrine are illustrated in the case of Wisconsin v. Yoder. In this case, the U.S. Supreme Court defended the rights of the Amish in Wisconsin to send their children to their own schools rather than the public schools.<sup>81</sup> In the Yoder case, the parents' rights to educate their children as they saw fit were defended by the Supreme Court. In contrast to

this, the case of Mark Painter of Ames, Iowa, was decided in favor of the grandparents' custody of a child in opposition to the child's natural father.<sup>82</sup> This case represented an overextension of the parens patriae principle. According to O'Neil and Ruddig, the state must typically shoulder a greater burden of justification for its interference with parents for the sake of their children than that which is generally borne by parents themselves in justification of their interference with children for the children's own sake.<sup>83</sup> This is because the action that courts or society may take, by its very nature, tends to be cumbersome and heavy-handed, and to constitute a threat to parental rights, particularly as to the right to supervise the upbringing of their own children, and the right to the free exercise of their own religion, an unavoidable influence on the developing attitudes of children. Although the burden of the state is characteristically more cumbersome than that shouldered by parents in conducting their own interventions, it should be the same general kind, and require the same rationale. In either case, the justification for intervention appeals to the eventual autonomy and to the good will of the child. The individual's right to self-determination and ultimately self-fulfillment has been frequently defended in philosophy. John Stuart Mill argued in his book On Liberty that

any attempt, however benevolent, on the part of the state to impose upon an individual some external conception of his own good is almost certain to be self-defeating, and that an adult's own good is "best provided for by allowing him to take his own means of pursuing it."<sup>84</sup>

Jonathan Glover, in his work, Causing Death and Saving Lives,<sup>85</sup> discusses some of the possible difficulties in such dilemmas as having to represent children when their interests appear to be in conflict with the interests of parents. According to Sharon Bishop, "even if children are not fully autonomous persons, when we recognize that they have, or will have, such self-determination, this puts significant constraints on how we may treat them."<sup>86</sup> Robert Young argues that one should reject the paternalistic approach to children; instead children and adolescents should be held competent to evaluate their own interests. He asserts that our primary emphasis should be upon protecting children's rights rather than talking of moral rights for children.<sup>87</sup> This point of view is in severe contrast to that of John Stuart Mill in his statement from On Liberty, "society has that absolute power over them during all the early portion of their existence: it has had the whole period of childhood and non-age in which to try, whether it could make them capable of rational conduct in life."<sup>88</sup>

Neill, Dennison, and Holt assert that children are perfectly capable of assessing and managing their own interests and therefore capable of playing a determinative role in shaping their education.<sup>89,90,91</sup> A. I. Melden asserts that the traditional view of legal rights as being primarily held only by adults, based upon their capacity to be rational and self-controlled, fails to recognize that others also have rights.<sup>92</sup> This is an incomplete approach because of the exclusion of children, who are considered not to have such rights as adults, even though adults, or moral agents, may have duties toward them. Melden argues that children can have rights, and that infants can be properly said to have rights even though they are not mature enough to participate in specific moral activities.

What principles should guide decision-making in cases concerning children is not clearly defined in the Supreme Court decisions which, according to Laurence Houlgate, waver between granting children full legal status as "persons" and regarding them paternalistically.<sup>92</sup> In the community of education systems, teachers' duties and authority over children come into play. Victor Worsfold asserts that there are legitimate rights which students have vis-a-vis their teachers as a result of the specified duties to and authority over students which teachers hold.<sup>93</sup> He places this relationship in the context of a

Rawlsian contract grounded in the rights that proceed from "just institutions". This contract approach, according to R.S. Downie, is legitimized through the consent of the governed.<sup>94</sup> C.A. Wring suggests that granting rights to children in school may jeopardize the relationship of trust between children and teachers.<sup>95</sup> He nonetheless asserts that granting the irreducible value of persons and their interests, ends, and purposes should be taken seriously.

The rights of children, the rights of parents, and the rights of society, with regard to interests in the welfare of children and families, are linked to many philosophical questions about which there are no clear answers. A variety of approaches can be found, and these reflect concerns of freedom, the limited capacity of children to represent their own interests, the nature of the parent-child relationship, and the degree to which children can be legitimately viewed as a part of the personhood of the parent or as individuals in their own right. Finding a balance between the theoretical approaches and the practical exigencies which for each party seem so pressing is difficult. Guiding principles representing the interests of each and full opportunity for each to pursue his maximum potential need to be delineated.

## Parent-Based Literature

Literature generated by the parents of handicapped children gives a rich picture of their problems as well as the joys of parenting the exceptional child. The insights of these parents into the process of conflict-resolution in disputes with the institutions of society can be gratifyingly enlightening. They present authentic perspectives since the parents have actually lived through the experiences they write about and have even waged hard-fought battles with prejudice and bureaucratic systems.

Harris presents the concerns of single parents with handicapped children when he wrote the story of his deaf daughter.<sup>96</sup> Similarly, Browne recounted her struggles as a single parent contending with society to secure the educational rights of her child.<sup>97</sup> Park presents the interests of the exceptional child raised in a large family,<sup>98</sup> as did the DeBolts, albeit a large family (21 children) of adopted children.<sup>99</sup> Some of the parents who have written about their experiences have professional backgrounds. The Gunthers, the Masseies, and Browne are examples of this group.<sup>97,100,101</sup> Paterson and the Colemans describe rearing a handicapped child from the perspective

of the Black family.<sup>102,103</sup> A strong religious orientation is represented by Rabbi Agress<sup>104</sup> and by Woodson, who writes about her children with cystic fibrosis.<sup>105</sup> Siedick and Poole address the concerns of children who suffer the consequences of organ transplants.<sup>106,107</sup> Clarke deals with learning disabilities.<sup>108</sup>

Some parents write about their experiences in effecting significant changes in provisions for children with the problems their own children have faced. Killia, who wrote in 1982 about her child with cerebral palsy, started a movement which has dramatically benefitted other children with the same condition.

There are recurrent themes in the books written by the parents of handicapped children. Although each author approaches the problem differently, each contributes to the general picture of parenting exceptional children. Some have a realistic approach to disability and generally provide a frank and honest portrayal of what it's like to live with a disability. These parents show us how they deal with medical impairments and recount the responses of family members to disability. They talk as well about their relationships with physicians, nurses, and teachers. These books are especially valuable to other parents who, when they have a handicapped child, can relate to these accounts. In the case of those books by parents who are

themselves professionals in the helping professions (social services, nursing, medicine), a greater amount of information is provided which is of special use to educators and rehabilitation personnel. Jablow's book about her daughter with Down's Syndrome emphasizes child development and includes information about sibling reactions from her own family.<sup>109</sup> Lund, who teaches at the college level, offers an account which is filled with descriptions of useful techniques for dealing with an autistic child.<sup>110</sup> Stimulating questions for discussion are provided by the Turnbull's book, Parents Speak Out.<sup>111</sup>

Optimism, in dealing with the demands of society and gaining services for children, is found in many of the books and articles written by parents. Siedick, for example, recounts the arduous and difficult process of a kidney dialysis regimen for her son.<sup>106</sup> Nonetheless, the end result is an optimistic approach to parenting in a difficult situation. Parents offer creative and inventive ways of coping with the problems of their disabled children. Most, indeed, will say that they are better people because of their struggle. They have received more than they have given from the experience. For those on the outside, the picture is undeniably one of extreme physical and financial demands upon the resources of the family. Some parents describe how they have endured a difficult

road in going from physician to physician trying to find an accurate diagnosis for the condition of their child, finding too often that they have been provided with mistaken, inaccurate, and ambiguous descriptions. Andersen, for example, describes the unbelievable insensitivity of a physician examining her seven month-old child to confirm the feared diagnosis.<sup>112</sup> When parents do have a good experience with professionals, they express their gratitude liberally. They are even comforted when the news is bad, as long as it is accurate. Pringle, for example, describes the doctor who cared for his son in a long battle against leukemia as practically being a member of the family, and he and his wife expressed gratitude and affection for his care.<sup>113</sup>

In Plummer's book, Give Every Day a Chance, the particular insensitivity to hospitalized children is noted.<sup>114</sup> Her child, with osteogenesis imperfecta, endured so many lonely and painful hours in hospital rooms. It is hoped that the writings of Mrs. Plummer will give impetus to changes in the approaches of hospital personnel to children with such difficulties.

The quests of parents to get their children admitted to schools and to secure the appropriate education for them are illustrated in Jablow's book.<sup>109</sup> Through a particularly ironic situation, a child with Down's Syndrome tested too

high for special education programming. The Masseies, whose son had hemophilia, found school personnel reluctant to cooperate in meeting the special needs of their child.<sup>101</sup> Marital stress, as a result of the extraordinary demands that a handicapped child places upon the family, illustrated by Featherstone, reminds us that "few couples agree at each fork in the road, even when the children are normal and the choice is ordinary. Disability raises the stakes in the conflict."<sup>115</sup>

There are emotional ambivalences which are probably not too different in kind from those any other parents experience, but certainly are far more intense when there is a handicapped child in the family. Parents at times feel singled out for a such a different fate. "Why me?" is the title of Agress's book.<sup>104</sup> Parents find themselves tortured with recriminations. Segal reproached himself, upon contemplating his cerebral palsied daughter, "Why didn't I perceive the problem? Maybe I could have saved those few crucial minutes that caused this lifetime of injury."<sup>116</sup>

The disabled children have their anxieties too. Many authors recount the substance of their handicapped children's expressions of frustration. DeFord's daughter, who suffered from life-threatening cystic fibrosis, after a frolicking game with her father, exclaimed, "Oh, Daddy, wouldn't it have been great?"<sup>117</sup>

The guilt that parents experience, how they relate that guilt, and how that guilt is perceived by professionals is a subject dealt with in several books. Featherstone, for example, writes, "I believe that Jody's toxoplasmosis was my fault. The disease seemed a judgment on my life and character."<sup>115</sup>

In general, one cannot hope to conduct a valid examination of the conflicts arising between families and society in the course of rearing handicapped children without paying close attention to the expressions of the parents themselves, both in writing and in personal interviews. In most cases, parents are the ones who spend the most time with their handicapped children, and therefore have a special insight into their needs and concerns. Wherever good working solutions to the conflicts between parents and society are found, it is never without the parents' participation in and implementation of the solution that the child can be fully benefited.

## The Perspective of Educators

How the presence of a handicapped child affects family life, and how family life affects the handicapped child in the school are special concerns to educators today. Children are seen as parts of a whole family process. This approach reflects the family-therapy psychoanalytic approach of Carl Whittaker who always insisted that treating an individual without involving the entire family was a futile exercise. This attitude is relatively new on the horizon and has gradually become more evident in the literature of the last twenty years.

When we look back at early texts on special education from the sixties and early seventies, we find that the family is rarely mentioned and then only peripherally. The most popular texts used in teacher training colleges still give little attention to the parental role. The two most popular texts used in the early seventies, Cruickshank and Johnson's Education of Exceptional Children and Youth<sup>118</sup> and Dunn's Exceptional Children in the Schools<sup>119</sup> had no chapters on parents.

Articles which addressed concerns of educators with regard to parent cooperation in the sixties and early

seventies tended to represent an anticipation of psychological malfunction and the expectation of little positive input from parents in the learning processes of children with handicaps. Clark and Hall's work on the utilization of parents in the behavior modification process is exceptional for its time, and marked the beginning of a gradually developing trend toward greater recognition of the importance of the parent's role.<sup>120</sup> In 1970, Sheila Hewett and John and Elizabeth Newson produced The Family and the Handicapped Child,<sup>121</sup> which studied cerebral palsied children in their homes. This work describes British families as examined from a school, social work, and educational perspective. Concerns of familial stress, community resources, and parental contribution to educational programming are discussed. On the whole, however, parents are presented as weak and ineffectual participants without the necessary training to make a significant contribution. Parents are portrayed as a part of the problem rather than a part of the solution.

Koch and Dobson wrote The Mentally Retarded Child and His Family in 1971.<sup>122</sup> It is a book of readings from several authors on a range of related subjects in the areas of etiology, education, psycho-social aspects, and community services. There is one chapter related specifically to the family, by Sylvia Schild. Dr. Schild

investigates the backgrounds of families who have mentally retarded children and finds that parental reaction to a child's mental retardation may be guilt or ambivalence. Because of the child's effect on the family as a whole the family itself is seen as one aspect of the problem which retardation presents rather than as a positive resource for the child. Dr. Shield quotes, however, from Begab, who said in 1963:

An important concept in child development is that the rate of intellectual growth can be changed--up or down--by altering the child's life experience. Among these life circumstances, none are more crucial than those encountered within the family circle. ...Indeed, the impact of intra-family relationships on the mental growth and behavior of the retarded child is particularly vital, for it may not only raise or lower performance but may determine in some instances whether the child is not to be classed as retarded.

John N. and Nellie Enders-Carver produced an interesting study of families of retarded children that was prompted by their interest in their own retarded child, David.<sup>123</sup> They describe the process of parents' discovery that their child is mentally retarded and how parents react to this. They talk about the different categories of mental retardation, the terms and clinical types, and the care problems that retardation presents. They also offer graphic accounts by other parents in their own words as to how their child's condition or behavior affects the functioning

of their families. They devote a chapter to life in the nuclear family and discuss how it is modified by the presence of a severely retarded child. They describe how parents behave toward the child and toward each other in their attempt to deal with the problems presented by the child's handicap. They also discuss the siblings of mentally retarded children, how they behave toward one another, and how they behave towards their retarded sibling. In another chapter they discuss the interactions between the family and those beyond the home and how the presence of a retarded child affects those relationships. They talk about how family finances are affected and how their communications with neighbors are affected. They discuss the conflicts between families and other outside organizations, schools, social agencies, churches, and the participation of the family in activities with these groups. They discuss the feelings of parents who confront the need to place their children in an institution, their ambivalent feelings, the aggravation of problems that arise during their long waiting periods to find a place for their child, and the changes at home that are made in preparation for the child's departure. They discuss the feelings that are aroused in conjunction with the event of the child's going to the institution. They also discuss readjustment in the family after the child has been placed in an

institution, and the readjustment of the child to his institution and his new life in the institution. Their approach to institutionalization is a positive one. The material they used for this book is gleaned from their surveys of families with mentally retarded children. The book is based on the results of surveys of thirty families who answered seventy-six questions. These authors provide a useful text which should assist those attempting to understand the parents' point of view and what they must go through in their search for services for their handicapped children.

Ved P. Varma edited Stresses In Children in 1973.<sup>124</sup>

It is a compilation of the works of twelve authors who discuss handicapped children in ordinary schools, psychotic children, slow-learning children, delinquent and maladjusted children, bereaved children, adopted children, immigrant children, injury-prone children, blind children, partially-sighted children, deaf and partially-hearing children, and children with physical handicaps. In each of these chapters, the stresses experienced by the families of children with handicaps are discussed from the point of view of a professional observing from the outside.

The third edition of Max Hutt and Robin Gibbey's The Mentally Retarded Child: Development, Education, and Treatment<sup>125</sup> contains a chapter devoted entirely to

parental reactions and family problems. The cases reviewed attest to the professionals' recognition of the importance of the parent's role. Nonetheless, the parent is seen as an additional patient, an additional student, and an additional problem in the life of the handicapped child. This chapter includes such subtitles as Parental Reactions of Rejection and Hostility, Marital Discord, Narcissistic Involvements, Dependency Reactions, Reactions to the Community, Guilt Feeling of Parents, General Family Problems, Treatment of Parental Family Problems, Parental Treatment Through Education and Guidance, Emotional Needs of Parents, Parental Treatment Through Psychotherapy, Parental Problems Difficult of Resolution.

In 1979, Milton Seligman produced Strategies For Helping Parents of Exceptional Children, A Guide For Teachers.<sup>126</sup> He discusses candidly the teacher's role as a facilitator, how parents and teachers view one another, and how one should understand the dynamics of families with an exceptional child. He offers specific strategies useful in working with parents of exceptional children and techniques for working with parents who are "problem parents." He includes an appendix of resources to help teachers help parents. Parents are seen as important contributors in the educational life of their handicapped children. This evaluation of parents is more open than that found in

earlier texts and pays more respect to the capacity of parents to contribute. Milton Seligman's book is a practical guide containing many useful hints for teachers who want to work closely with parents in order to maximize the potential of their handicapped children. In 1985, Hobbs, Perrin, and Ireys produced Chronically Ill Children and Their Families.<sup>127</sup> This text focusses primarily on the chronically ill child. Families are represented only peripherally. The authors' emphasis is on the development of improved policy for providing the benefits that families of children with chronic illness need and on the nature of ethical dilemmas in the medical management of chronic illness in children.

Recently off the press is Lee Combrinck-Graham's book, Children in Family Contexts, Perspectives on Treatment.<sup>126</sup> This is a compilation from twenty-five authors who contribute works regarding children in family contexts. Most of the children they are speaking of are those who are handicapped through mental illness, although there is one chapter by Janet Fievers that deals specifically with physical and cognitive handicaps. The book is designed as an approach to family therapy from a systems point of view, based upon the premise that the family is a child's primary resource system. But the audience for this approach is that of family therapists who are encouraged to help families

with physical and cognitive handicaps by identifying their unique experiences and coping patterns, and by directing efforts at freeing families from the constraints and misconceptions about the nature and cause of handicaps, to utilize motivations, problem-solving skills, and values of all family members, including the handicapped children. Families are seen as positive, strength-bearing systems capable, for the most part, of coping with the extraordinary experience of having a handicapped child. It is emphasized that the strengths that lie within the family can carry them beyond the moments of difficulty inevitably experienced in these situations. The authors caution that if therapists approach the system of the family without proper respect for the unique ways that families find to handle their special situations, then the therapist may stand a good chance of becoming part of the problem rather than assisting with solutions. This text is representative of the most current trends in the approach to families and handicapped children.

Over the years professionals have "studied" families of children with handicaps. They have examined relationships between parents and children, drawn conclusions based upon the samples examined, and made generalizations which have affected the outlook of professionals who examine their studies. Typical is the report

made by Kenney, who studied mother and retarded child relationships.<sup>128</sup> She compared four groups of mothers with respect to their levels of ego development and their authoritarianism in child-rearing practices. The groups consisted of mothers and their children who were educable and adjusted in school; educable but maladjusted in school; non-retarded and adjusted in school; and non-retarded but maladjusted in school. Kenney concluded that mothers of maladjusted retarded children tended to be less mature and had lower levels of ego development than did a matched group of mothers of maladjusted, non-retarded children. The implication Kenney saw was that a mother's ability to understand and accept a retarded child relates to the development of her own personality as she deals with the varied stress situations that the introduction of a deviant child into the family inevitably brings. Coping is described by Kenney as a very complicated process. She describes the sequence of responding to stress situations as cyclical, and concludes that these stresses may have a cumulative effect upon the mothers' internal personality. Kenney's study of parental stress concluded that parents respond in one of three major ways to the stress of coping with a handicapped child, to accept, deny, or disguise the child's mental retardation.

The report of a symposium on counseling the mentally retarded and their parents, published in the Journal of Clinical Psychology,<sup>129</sup> found that parental difficulties in dealing with retarded children stemmed from the setting of unrealistically high goals for the young child; over-protection of the child; overindulgence of the child; and maladjustment of the parents, manifested as alcoholism or emotional disturbance.

Meyerowitz studied parents' "awareness" of mental retardation in their children.<sup>130</sup> He examined the parents of 186 children who were about to enter the first grade in public school. The children had Binet I.Q.'s ranging from 60 to 85 and had been placed in either regular or special education classrooms by random assignment. Each family was interviewed three times during a two-year period. The first interview took place about one month after the child had begun school. The second interview was at the end of the first school year, and the third interview was at the end of the child's second school year. The interview questions related to the parents' awareness of the limited abilities of their retarded children. It was noted that the parents thought that their retarded children responded "obliquely" and immaturely to their environment. Parents had low expectations of their retarded children's completing school but did not seem to have concerns about the limitations of

their children after they attained adulthood. In fact, the parents' expectations for their children's professional and occupational performance was not statistically different from the expectations of matched criteria parents of normal children. The parents of children who were placed in special education classes appeared to have a greater awareness of their children's problem, but in spite of this, fifty-five percent of the parents were judged to be unaware of the limited abilities of their retarded children. In order to attain an effective resolution of the problems of stress and conflict between the families of retarded and other physically handicapped children and social systems the families deal with, there must be a reasonable understanding by parents, as well as by professionals as to the true capacities of the children. Given the varied ways that professionals interpret studies and the variety of statistics that are produced relative to the performance of retarded and handicapped children and the understanding of professionals with regard to the capacities and understandings of parents, it seems as though it will always be difficult to resolve the conflicts that arise between families and society in the endeavor to provide education for children with handicaps.

## Literature From Psychology and Counseling

Journals in the field of psychology and counseling abound in substantive articles on how to interview parents and how to conduct parent conferences. These articles commonly discuss provisions for reassurance of and support for parents. Working through specific problems is deemed a shared experience, and a more open and direct communication in a counseling relationship, is recommended. These articles are not generally written from the parents' point of view nor for the parents, nor do they advise what parents should expect from an interview or conference with a teacher or a doctor. Parents are generally ill-prepared for such meetings. Many writers refer to counseling and psychological intervention as conducted primarily in clinical or institutional settings with traditional psychotherapeutic techniques. Less restrictive writers view counseling as embracing almost any human relationship in which individuals or groups are working together to solve problems or to share experiences for growth and learning. Counseling usually begins when parents seek an accurate diagnosis of their child's defect beyond the medical interpretation of their pediatrician. Anderson describes

the "shopping behavior" of parents which often occurs as a result of seeking an accurate diagnosis.<sup>131</sup> This behavior refers to "parents making visits to the same professional or to a number of different professionals or clinics in such a manner that one visit follows another without resolution or a resolvable problem." For various reasons a great deal of time, energy, and money may be expended in this process. An initial diagnosis may be reviewed and found to be inaccurate or incomplete. Parents may decide to visit another professional or clinic. The most common reason, however, is that although the diagnosis was accurate, the parents either refuse to accept the results or the professional fails to adequately explain the results to the parents, thus setting up a situation of conflict between the family and the professional institutions of society. Barsh reports that many parents prefer team consultations, as opposed to single professionals, in order to compare opinions and check information.<sup>132</sup> Katz points out that parents may not feel inclined to ask questions and interact when confronted by several professionals in a large, informal group.<sup>133</sup> In interviews of twenty-three mothers of retarded children, Korch and Negrete investigate the types of visits that mothers make from the time of a retarded child's birth onward, and the degree of the mothers' satisfaction with these visits.<sup>134</sup> Out of 453

visits to various professional people, mothers are found to be satisfied with 75 percent of their visits. Some of the visits take place prior to any suspicion that something is wrong with the child. They do not appear to be initially negative toward professional help when that help is invoked for the usual injuries and illnesses of childhood. Their satisfaction decreases, however, with further diagnosis, and in later non-diagnostic visits to professionals for complaints that are not easily defined in the diagnosis of their child. Mothers commonly complain that although it is obvious that something is wrong with their child, they are often told that nothing is wrong, and professionals seem to lose interest in both the mothers and the children after several visits. The mothers complain that the amount of time professionals spend in examining their children is insufficient, and that the professionals do not take an adequate amount of time to explain the diagnosis to the mothers. The mothers are seldom offered guidance in dealing with their immediate problems, and they sometimes leave the interview with no hope for the future. This report reveals that professionals curtly instructed some parents of older children to institutionalize their child. Many mothers also state that the doctors do not seem to be as interested in the injuries and illnesses of their retarded children as they are in those of normal children. A study of 260

parents designed to assess the counseling parents receive reveals that only half of the parents were satisfied with the diagnosis received from the initial visit to the professional.<sup>135</sup> Hewett asserts that the manner in which handicapping conditions are interpreted to parents is a primary indication of the quality of any diagnostic clinic.<sup>136</sup> She describes two models. One, the virtuoso model, which offers a team of highly-trained specialists who meet with parents and provide detailed and thorough information on all facets of the handicapping condition which, although it facilitates communication between professionals, is often inadequate to convey information to parents. Parents are generally not impressed by a group of professionals who are trying to impress each other with their diagnostic skills, and parents seem to gain very little understanding or insight into the problem from hearing detailed laboratory reports and test results. A second model, an interaction model of interpreting diagnostic information to parents, appears to be preferable. Hewett stresses that diagnostic efforts are generally useless to the retarded child unless the results and implications are adequately explained to parents. "Certain terms glibly used by professionals to describe general levels of retardation are meaningless to most parents." Edgerton and Berconci, in their 1975 study, find

that the method of presentation and the type of handicapping condition strongly influence the amount of information mothers understand.<sup>137</sup> A study by Farber investigates the variables which determine whether recommendations made during child psychiatric consultations are carried out or not.<sup>138</sup> In this study the author found that fifty-two percent of the recommendations from the initial consultation are not carried out. Recommendations are most likely to be accepted if both parents are present, rather than a mother or a father alone. It also appears that more recommendations are followed when the child is under the age of nine, and far fewer when the child is over the age of thirteen. Parents are also more likely to follow recommendations when they have the opportunity to discuss the child's problem with others and are also far more inclined to follow recommendations if they agree with the professional's diagnosis and evaluation of the problem. It is clear that unless parents understand and accept the information that is presented, very little can be done for the child. Kanner describes a counseling approach called academic reorientation.<sup>139</sup> This is used with remedial readers, and contains several important features designed to help children develop more desirable behavior.

Few studies concentrate exclusively on the concerns of parents. One exception is Millman's study which describes

open-ended group meetings in which ten to twelve parents of children with minimal brain dysfunction attend sixty or ninety minute sessions each week for as long as they desire.<sup>140</sup> Bricklin investigated groups of parents of children with learning disabilities.<sup>141</sup> In this study, new parents are seen individually, then with other new parents, and finally as part of an existing group. Usually parents of children with similar difficulties and age are placed together. During the meetings, parents acquire knowledge regarding particular learning problems and have the opportunity to share feelings. Bricklin points out that certain aspects of the sessions are often difficult for the parents since established ways of receiving and responding to their children are difficult to change. However, parents and children alike have the capacity to change, according to Bricklin. One of few studies using a control group is that of Lewis, who examines group counseling techniques with sixty-two parents of mentally retarded children.<sup>142</sup> The control group in this case did not participate in group counseling, nor in two objective tests. During ten weekly ninety-minute sessions for each of three groups, parents introduce and discuss topics in a non-structured atmosphere. The data from the study show that attitudes towards child-rearing improved for two of the three groups. Those parents not participating in group procedures had

"less enlightened attitudes." Lewis concludes that "parents seemed to emerge from the group experience with increased self-direction, confidence, and optimism, all of which are goals of counseling in general." Other studies based on parent participation and comparing the interventions of direct counseling with children and those of indirect counseling through teachers and parents are those of Taylor as well as those of Love, and Bugenthal<sup>143,144,145</sup> Each of these studies shows that children are more effectively counseled and change is more effectively facilitated through the use of teachers and parents in the counseling process, as opposed to direct counseling of children. The majority of studies concerned with counseling interventions and psychological therapy for the families of handicapped children in school environments are directed at assisting families or children in the process of adjusting to the problems presented by the child's handicap or the parent's adjustment to the handicap, rather than resolving conflicts between families and society. Nonetheless, in each study there appear to be variables taken into consideration which address certain stresses between families and society. In almost every case these conflicts are dealt with indirectly. For example, when parents appear to have difficulty understanding a technique used by a teacher or a therapist in assisting a child in a behavior-modification

program. counseling intervention may take the form of educational processes for the parents in order to reduce the stress and conflict between the family and the institution. Most of the research deals with children with behavioral disorders or certain learning disabilities, while other handicaps such as mental retardation and physical impairments have received relatively little attention.

The trend appears to be moving toward increasing parental participation in the counseling process, and there is an increased amount of attention, as studies and program descriptions have indicated, that parents must play an essential role in efforts to remediate their child's problems. Indeed, some studies have shown that parental counseling would be more beneficial in many situations than would direct therapy or remediation for the child.

There is a significant trend toward an increased focus on parent-child interactions in relationships. Parents and children are not counseled in isolation. Instead, a model is employed utilizing behavior modification techniques emphasizing the development of new patterns of behaving and interacting for both parents and children together. In this approach, parents themselves learn behavioral principles and techniques which are actively applied with their children at home and consequently promote desirable and

appropriate behaviors. This approach is in contrast with attempting to work indirectly through weeks or months of vague discussions about assumed causes such as guilt or rejection or fear in order to modify behavior.

Summary

The literature of psychology, education, law, philosophy, and the accounts of parents themselves regarding their concerns pertaining to the rearing of handicapped children is generally expressive of the concerns which each field deals with in the parenting process or in the remediation of difficulties that arise because of the interaction between parents and children or between parents and institutions. The author was nevertheless unable to find any specific works which deal exclusively with the resolution of conflicts between society and parents engaged in the rearing of handicapped children. Almost every work which is concerned with areas of parental or child behavior in the case of the handicapped child has an element of concern regarding the resolution of conflicts between families and schools, or families and hospitals, or families and other agencies designed to assist parents in the process of rearing their children. Some works which are designed to help parents develop the skills they need in addressing those conflicts that they have with social institutions because of the special needs of their children offer lessons in assertiveness and describe techniques for overcoming the

obstacles presented by those groups which by their nature and structure would inhibit the fulfillment of their child's full potential. One such work is Taking On The World, Empowering Strategies For Parents of Children With Disabilities by Joyce Slayton-Mitchell.<sup>146</sup> This text offers a basic course in assertiveness training designed primarily for mothers of handicapped children. It assists them in the process of taking on the world through taking on the family world first, then the medical world, the school world, the church world, the work world, the bureaucratic world, and then adjusting themselves to "stabilize," "mobilize," and "activize." Mitchell provides a very practical handbook for parents and gives many specific examples wherein parents can assert their own interests or the interests of their children and gain access to the services they require. The book appears to have great potential for helping parents who might otherwise be timid in approaching medical or educational professionals. Surely the conflicts between families and society relative to the rearing of handicapped children are multifaceted and numerous institutions with numerous orientations, be they medical, educational, psychological, religious, philosophical, or legal must be dealt with. Parents cannot be expected to have expertise in these areas. By the same token, neither can professionals in those various different fields have expertise as

parents, and certainly not as parents of handicapped children. The nurturing of an increased awareness on the part of society in general that parents have an important position in the lives of their children is therefore basic to the establishment of an environment in which the conflicts between the parents and society can be resolved.

## CHAPTER 3

### CIRCUMSTANCES AND PERCEPTIONS WHICH LEAD TO CONFLICT AND CASES DEMONSTRATING CONFLICT BETWEEN FAMILIES AND SOCIETY RELATIVE TO THE REARING OF HANDICAPPED CHILDREN

#### SOCIOLEGAL CONFLICTS

Conflicts may arise between the parents of handicapped children and professionals whose duties require them to take a special interest in such families. These conflicts stem from differences in attitude and reflect differences in interests that are grounded in the nature of their separate positions. Parents see their rights and duties from a different perspective than professionals do. Professionals view their duties and obligations towards children and families from a different perspective than parents do.

The rights and duties of parents are of special concern to all social service and legal professionals whose practices are child and family centered, but just as parents are not always perfect in the discharge of their

responsibilities, neither are the legal and social service professions. Although laws and administrative regulations may be established specifically to insure the best interests of children, the execution of legal or social service interventions can result in situations detrimental to the children they are intended to serve. This ironic result does not diminish the propriety of the interest or the need to intervene effectively on behalf of children whose needs are not met by parents.

When in the perception of society, parents fail to provide appropriate care for their children, then society attempts to intervene. Unfortunately there is often little consensus about what is best or even good for all children. This lack of consensus seems to be evident throughout human history, in every culture, location, or circumstance. Society's view of what is acceptable governance of children on the part of parents has changed over the years within cultures and nationalities and continues to vary from group to group and from legal system to legal system. There is variety in the approaches to human psychology that guide judgment in legislation affecting children and families. There is variety in methodological approach to problems of child and family psychology and welfare.

The norms of child governance are grounded in parental rights and obligations which may be viewed differently by

parents and by professionals. In general, parental rights may be respected on the basis of the fact of biological reproduction. The offspring is, in effect, a literal part of the body of the parent. The physical association is naturally accompanied by a psychological association. But the physical and psychological development of the child cannot be assured by the mere fact that a biological parent exists. There must be a bond of caring and communication between parent and child. Because of the physical and emotional frailty of human infant existence, parenting is a long-term commitment at the very least. Where there is a failure on the part of the parent, either because of circumstances within the parent's control or circumstances beyond the parent's control, then society expresses its interest by intervention on behalf of the child. Whether the child is found in the home of its biological parents or in the home of its legally adoptive parents, the respect of society for parental rights and the concern of society for the welfare of the child may come into conflict when a failure to meet the minimal standards society deems necessary for child growth and development is evident. In spite of a harmful or potentially harmful situation for a child at home, the intervention of society may result in little more than the imposition of legal authority to

destroy the last threads of a potentially wholesome parent-child relationship, leaving the child with less than it could hope for before the intervention.

One instance of intervention that receives a great deal of public attention today is that following a report of child abuse. An examination of the statistical record of the incidence of child abuse in the United States over the past two decades and a number of interventions on the part of social service agencies point to a growing problem of what appears to be too little effective intervention and services which come too late to be truly effective. Too often children are returned to the parents who abused them even though the chances of repeated abuse are great. Even life threatening abuses may not preclude the return of a child to its parents. Children who are neglected nutritionally to the point of starvation may not necessarily be safe from further abuses. Even after a child is taken from an abusive parent, that parent may have a continuing right to visit and interfere in the life of the child.

On the other hand, society may be critical of its appointed authorities and accuse them of interfering too much or without sufficient cause into the lives of families. When some intervention may be deemed necessary, the extremes of familial disruption and the placement of

children in separate foster homes may be more harmful than the neglect they experienced at home. In some cases there may be legal representation of children and parents, thus precluding personal contact. In cases of medical neglect, decisions may be made on the basis of medical orientations of judges and other juvenile authorities without consideration of the preferences of the parents. There are even cases where parents seeking legitimate medical care for their children were prevented from obtaining necessary physician's services because of some social service authority's suspicion that some abuse had taken place and then the suspicions were found to be unjustified.

In the event that abuse or neglect is suspected, intervention includes placement of children in foster homes. The feelings of children, their needs for security and consistent role models, and their need for parents who have confidence in their own ability to provide a continuing and nurturing environment may be lacking in foster placements that move children, separated from their siblings, from home to home. By returning children to biological parents after many years in foster care without regard for the attachments formed in a long-term placement, authorities may do great damage to the child's psychological development.

The great potential for harm where too little is done and the concern for potential harm where too much is done necessitate the provision of some basis for judgment and some system to the decision-making process that offers protections, checks and balances. In spite of standards of fair warning and restrictions on the exercise of power, the state has not always been able to curb the zeal of social workers and insure that intervention is made only where there is a capacity to provide a "less detrimental alternative" to the situation of abuse or neglect in which they find the child. The interventions of society must be restricted to objectively definable grounds, with the result that in some children in need of protective services are being left out in order to prevent the arbitrary inclusion of other families where intervention would be harmful. In the United States today one is more likely to find the state erring on the side of non-intrusiveness. The recommendations of Goldstein, Freud and Solnit are for "the correlative principles of least intrusive invocation of the law, least-intrusive adjudication and least intrusive disposition."<sup>147</sup> These principles are applied to family units as they are found to exist and not necessarily as they may be legally constituted or biologically founded. Goldstein, et al, recommend that we attempt to regard each

situation from the child's point of view and with respect for age, developmental phase and background.

Commentary on the limitation of society to substitute for parents is not new. Jeremy Bentham, writing in 1840, expressed an opinion on the status of children which reflects the need for watchful care on the part of parents and the limited ability of society to provide substitutes for parents:

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The feebleness of infancy demands a continual protection. Everything must be done for an imperfect being, which as yet does nothing for itself. The complete development of its physical powers takes many years; that of its intellectual faculties is still slower. At a certain age, it has already strength and passions, without experience enough to regulate them. Too sensitive to present impulses, too negligent of the future, such a being must be kept under an authority more immediate than that of the laws...<sup>148</sup>

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Parents, being those closest to their children, are generally accepted to be the appropriate authority for the rearing of children. They act as representatives of their children before the law and introduce their children to the institutions of society. This authority may be based on a biological relationship and reflect the physical connection between parents and children. Freud saw the human infant as "sent into the world in a less finished state," compared to other species and therefore more subject to "the dangers of the world."<sup>149</sup> This situation necessitates, in Freud's

view. a burden of responsibility upon parents which will result in the growth of a psychological bonding stemming from a physical dependence. The pleasure for the child in being cared for by the parent leads to an attachment to the caregiver. This leads to the wish for approval and love, a desire on the part of the child to please the parent in order to gain more approval. The child's responsiveness to educational efforts rests on this reciprocal basis. Identification with parents results from the child's appreciation of the love relationship and gives rise to impulse control and socialization.<sup>150</sup> After childhood, the years of adolescence present the painful struggle to become independent and gain a separate identity.<sup>151</sup>

It is indeed these circumstances which necessitate familial privacy and autonomy according to Goldstein, Freud and Solnit.<sup>147</sup> When society intervenes in the affairs of the family and the family's integrity is weakened in the eyes of the child, then the child's capacity to have his needs met deteriorates. There may be a premature destruction of the child's belief and trust in the security and power of his parents. This is invariably detrimental to the development of the child. For this reason the law must do everything possible to maintain a recognition of the privacy rights of the family.

Goldstein, et al., point to two purposes as the basis of freedom from state intrusion into the affairs of the family: that parents must enjoy an "uninterrupted opportunity to meet the developing physical and emotional needs of their child so as to establish the familial bonds critical to every child's healthy growth and development," and to insure the "continuing maintenance of these family ties--of psychological parent-child relationships--once they have been established."<sup>147</sup>

Unfortunately, the mere assignment of the parent-child relationship by virtue of birth or adoption does not guarantee the establishment of significant psychological ties. When parents are separated from their children for long periods of time, or when children are abandoned, the legal or natural tie does not prevent the establishment of psychological bonds with others who do not share any legal rights relative to the child. According to Goldstein, et al., such bonds should enjoy the same consideration and protection of privacy as accorded to functioning biological or adoptive relationships. In the 1977 case of Smith v. Organization of Foster Families, a U.S. district court declared:

A biological relationship is not present in the case of the usual foster family. But biological relationships are not exclusive determination of the existence of a family. The basic foundation of the family in our society, the marriage relationship, is of course not a matter of blood relationship... (T)he importance of the familial relationship, to

the individuals involved and to the society, stems from the emotional attachments that derive from intimacy of daily association, and from the role it plays in 'promot(ing) a way of life' through the instruction of children, Wisconsin v. Yoder, 406 U.S. 205, 231-33 (1972), as well as from the fact of blood relationship. No one would seriously dispute that a deeply loving and interdependent relationship between an adult and a child in his or her care may exist even in the absence of a blood relationship. At least where a child has been placed in foster care as an infant, has never known his natural parents, and has remained continuously for several years in the care of the same foster parents, it is natural that the foster family should hold the same place in the emotional life of the foster child, and fulfill the same socializing functions as a natural family. For this reason we cannot dismiss the foster family as a mere collection of unrelated individuals.<sup>152</sup>

Goldstein, et al., find the state an inadequate parental substitute. "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."<sup>147</sup> Recognizing, however, the critical nature of human growth and development and how essential autonomous parents are in the life of a young child, society also recognizes that some parents' failures in fulfilling their obligations and duties to their children must be tolerated. Family privacy, a basic element of American society and an essential part of parental autonomy, may mask an exploitation of the position of power held by parents over their children.

parental hatred for children, unconsciously or consciously expressed anger towards others but directed at children, is a real situation in many families today. When parental anger becomes potentially harmful to children then privacy is not a benefit but is rather a threat to the child. Thus, society may justify the expression of its interest by intervention. The danger here is that society can substitute one harm for another. Because of the inability of the law to provide the necessary combination of reciprocal affection, the feeling of being wanted and the stimulation of inborn capacities, a child's development may be at risk when a child is removed from its parents. For these reasons Goldstein, et al., ask the question: "What ought to be established and by what procedure before the 'best interests of the child' can be invoked over the rights of parents to autonomy, the rights of children to autonomous parents, and the rights of both parents and children to family privacy?"<sup>147</sup>

When is it truly justifiable for society to intervene on behalf of a child? There are several criteria that any intrusive action must meet, according to Goldstein, et al.: when there is an over-riding societal interest, as in the case of immunization requirements for children, or the requirement to receive education. Parents are given "fair warning" that this is the expectation of society, and the

law will intervene if there is a failure on the part of parents to honor these requirements of society. When interventions are considered necessary, there are protections for the family and procedures of due process to protect the autonomy of the family in the case of a dispute. Even the cases mentioned, education and immunization, have been disputed.

Unlike the obvious societal interests of education and community health, those concerns related to the personal lives of family members and occurrences within the walls of the home are more difficult to express in terms of legislation, and the enforcement of laws in such areas is even more difficult. Laws regarding the "abuse" and "neglect" of children are by their very nature imprecise, and "legislative enactments which simply make 'denial of proper care' the standard for investigating or determining 'neglect,' and 'significant change of circumstances' the standard for modifying custody after divorce, provide neither meaningful advance warning to parents nor adequate guidance for courts or administrative agencies."<sup>153</sup>

This unlimited parens patriae discretion in familial life is used to enforce the interests of society and supplant parental judgment with standards of intervention. Unwarranted intrusions on family integrity must therefore be prevented by fair warning for parents and children and

by restrictions on the powers of state officials. Goldstein asks:

What must be established to overcome the strong presumptions in law (a) that parents have the right, the capacity, and the obligation to care for their children in accord with their own notions of child rearing; and (b) that children have the right to uninterrupted and permanent membership in a family with such parents?<sup>147</sup>

This is the question that legislators must answer prospectively.

Parents who are convicted of a sexual offense against their child or who are acquitted by reason of insanity present grounds for state intervention on behalf of the child. These grounds refer to infringements upon a child's psychological development and recognize that a child's sexual development is not in the same category as an adult's and needs to be free from premature erotic experiences or the seductions of a disturbed parent.

Goldstein, et al., suggest that investigations into allegations of sexual abuse must proceed with extreme caution and with respect for the integrity of the family. Only after sexual abuse has been proved should any action be taken to provide an alternative placement for the child.

This does not refer to physical abuse. The following example illustrates the importance of respect for family integrity:

Michelle was admitted to Lincoln Hospital "with severe injury to the vaginal area...the hospital reported Michelle as an abused child whose injuries were most likely the result of rape, and the circumstances surrounding this incident were unexplained by the parents. The undisputed evidence shows that these allegations are misleading in significant respects, that on the afternoon of the incident in issue--which was a partial school holiday--Maurice was in and out of the home doing errands, Marie was washing dishes, and Michelle was first using the vacuum cleaner and then taking a bath. Marie heard Michelle exclaim from the bathroom and saw that she was bleeding. Mrs. Vulon came home shortly thereafter, and although the bleeding was not extreme took Michelle to Prospect Hospital.... The hospital physician called by petitioner testified that the bleeding was attributable to a laceration of the vagina of about an inch; that he could not estimate the source of the laceration with any certainty except that rape was not the cause; that the condition was probably due to "trauma" of some other type and could have been self-inflicted. The erroneous suspicion of rape--which persisted apparently because of a failure to consult this knowledgeable physician--underlay petitioner's allegation as to the parents' failure to explain the circumstances of Michelle's bleeding. Mrs. Vulon did explain the circumstances to petitioner and other interrogators to the extent she could ascertain them from the children. There is no indication that she knew or could have known anything more than she recounted. What she failed to do was to accept the mistaken allegations of rape and to aid the Bureau in its exploration of this suspicion. According to petitioner, the parents "refused to believe that their child had been raped. They stated that they would not go into any conversation about rape with their children. They explained that in their country, a child did not learn about sex until the child was about 15 years of age; nor did the mother want me to discuss this with the child.... Petitioner's attorney argued that neglect should be

inferred from the parental failure to explain the basis for Michelle's' bleeding...Prosecution of this petition was largely attributable, it is clear, to the parents' refusal of Bureau's request that they consent to their children's examination by the Court psychiatrist. Such examination apparently was viewed in part by the Bureau as a possible method of determining whether Maurice committed the non-existent rape. So intent was the Bureau on its proposal that its attorney approached the Court ex parte before the hearing to ask it to order such examinations...

This Court believes from observation of these parents and children that they have an affectionate, mutually-respecting and beneficial relationship. A good faith appraisal by responsible and concerned parents, such as the Vulons, of the best way to handle a problem of child development on which reasonable men can differ in their value judgments, is not neglect.... While it was necessary and proper to conduct some investigation of whether Michelle's unusual condition indicated abuse or lack of care, the State cannot, without more justification than here appears, override the liberty of the parents, protected by the Constitution, to bring up their children <sup>154</sup>as they think best....Petition dismissed.

According to Goldstein, et al., in the above case there was no grounds for intervention. The confidential relationship between parent, patient, and physician should be safeguarded. Parents should not have to fear that if they seek medical care for their children they will risk an investigation by the state. Little has been done to truly protect children through laws that require professionals to report suspected child abuse.

When parents inflict injury, repeatedly fail to prevent injury, or attempt to inflict injury on a child,

then there are grounds for intervention by the state. Such injury may be passive, as in the case of long confinements or starvation, or direct, as in the case of beatings. Children cannot judge what is dangerous to them. They may willingly drink poisons or climb and fall from dangerous heights if unsupervised. Parents must value and protect the well-being of their children as they value and protect their own well-being. When parents are repeatedly neglectful of their children or deliberately harmful to them, then the state has an obligation to protect the child from injury. According to Goldstein, there must be "serious bodily injury" and not just the appearance of emotional or psychological neglect which is too imprecise to warrant intrusive actions.<sup>147</sup>

The following examples illustrate the need for restrictions in defining parental abuse:

Miss Shay, a 22-year-old unmarried "hippy", as she neared the end of an uneventful pregnancy, decided to keep her baby, having initially expressed the wish to have it adopted. The hospital social worker reported to the state's protective services that there was reason to feel worried about the child's safety and well-being because of Miss Shay's change of mind about adoption and because she was eccentric in her attire as well as her attitude toward food and cleanliness.

...Miss Shay's "peculiar behavior" was of considerable concern to the protective services. In order to have time to discuss with the mother how babies should be cared for, the social worker convinced her that it would be desirable to hospitalize the child for observation in the ward for abused and neglected children--even though, in the

opinion of the baby's doctor and the public health nurse, the infant girl was "well nourished and behaving normally." One evening, fearful of losing her child, the mother took the baby and walked out of the hospital. Unable to find public transportation, she began hitchhiking home with the baby in her arms. The police picked them up on the road.

...Two weeks later the social worker petitioned the court to place the baby under the guardianship of the Welfare Commissioner. The court granted the petition, and the two-month-old infant was placed in a foster home.<sup>147</sup>

Clearly, guidelines could preclude some of the difficulties that can result from such interventions as described above. Nonetheless, guidelines are subject to interpretation. The statute cited above regarding what constitutes neglect was obviously broad enough to allow for a range of interpretations. Parenting is not a precise science, and there is as much variety in approaches to parenting as there are parents in the world. In order to have true meaning, guidelines may need to address principles of intervention that recognize parental rights.

A justification for intervention is the safeguarding of the child's physical well-being through necessary medical treatment. Should parents refuse to authorize medical care which is non-experimental and necessary to sustain the life of the child, there is grounds for intervention by the state. Goldstein includes the requirement that "the anticipated result of treatment is what society would want for every child--a chance for normal healthy growth or a life worth living."<sup>147</sup> When

death would not result from the failure to provide medical intervention then there would be no legal justification for intervention to force parents to relinquish their authority.

Goldstein, et al., place the total burden for the life or death decision in the hands of the parents if there is any question as to the quality of life of the child in question. According to them, physicians and/or the state should not intervene when parents refuse to authorize treatment unless there is clear concensus that the life and functioning of the child will in all liklihood be "normal" after treatment.

No one has a greater right or responsibility, nor can anyone be presumed to be in a better position, than a child's parents to decide what course to pursue if the medical experts disagree about treatment. The same is true if there is no general agreement in society that the outcome of a proven treatment is clearly preferable to the outcome of no treatment. Put somewhat more starkly, how can parents in such situations be judged to give the wrong answer when there is no way of knowing the right answer? In these circumstances, if the law's guarantee of freedom of belief is to be meaningful, parents must have the right to act on their belief within the privacy of their family. The burden must always be on the state to establish that what may be right<sup>147</sup> for them is necessarily right for others.

The grounds offered by Goldstein, et al., are concerned with unacceptable judgments on the part of parents with regard to medical treatment necessary to

preserve the life of the child. An example of intervention which met the criteria of the suggested grounds is that of Judge Murphy of the Superior Court of the District of Columbia in In re Pogue.<sup>155</sup> Blood transfusions to save the life of an otherwise normal infant were authorized by the court when the mother refused to authorize the transfusion either for either herself or for the child. Judge Murphy did not, however, order blood transfusions for the mother. The decision was made to allow the child to live to the age of majority in order to make such decisions for himself. The parents were declared temporarily incompetent to care for the children, but the mother's right to refuse treatment was acknowledged.

Accepting the grounds for intervention offered by Goldstein would also allow parents to refuse medical intervention for a child with a congenital malformation where treatment would save its life but offer no chance of cure. Here, Raymond Duff, a pediatrician, is referred to:

Families know their values, priorities and resources better than anyone else. Presumably they, with the doctor, can make the better choices as a private affair. Certainly, they, more than anyone else, must live with the consequences...If they cannot cope adequately with the child and their other responsibilities and survive as a family, they may feel that the death option is a forced choice...But that is not necessarily bad, and who knows of a better way?<sup>156</sup>

Goldstein, et al., place the responsibility for providing those services a handicapped child will require, if it is treated and its life is preserved, upon the shoulders of society if parents reject treatment. If the parents resign totally from responsibility for the child when the state insists upon treatment, then the state is also accountable to find an adequate placement for the child. This creates a serious dilemma because the state itself has no proper capacity to be a parent, and the availability of adoptive parents for handicapped children is limited.

In those cases where the state would seek to compel a handicapped child to undergo medical treatment against the wishes of his parents and where death is not an issue, but rather the correction of some deformity, Goldstein, et al., recommend respect for the autonomous decision of the parents:

Under the Family Court Act of New York, Judge Elwyn declared 15-year-old Kevin Sampson "a neglected child." He made this finding in order to establish his authority to veto a decision by Kevin's mother not to force her son to undergo a series of operations which had been recommended by the Commissioner of Health and by duly qualified surgeons to correct a facial condition called neurofibromatosis.

...He wrote: "I am persuaded that if this court is to meet its responsibilities to this boy it can neither shift the responsibility for the ultimate decision onto his shoulders nor can it permit his mother...to stand in the way of attaining through corrective surgery whatever chance he may have for a

normal, happy existence, which...is difficult of attainment under the most propitious circumstances, but will unquestionably be impossible if the disfigurement is not corrected.<sup>147</sup>

In the view of Goldstein, et al., Genuine humility would not have allowed a judge to believe that he, rather than Kevin's mother, was best qualified to determine the meaning of "a normal and happy existence" for her son.

In the case of Iafelice by Iafelice v. Zarafu,<sup>157</sup> the court held that "Physician's failure to disclose that an infant would require institutional care for the rest of her life even if a life-saving operation was successful does not create liability for the "wrongful life" of the child based upon a lack of informed consent."

Wrongful death has always been an issue in the law. But wrongful life is a relatively new concept. On October 2, 1980, Renee Iafelice was born prematurely and suffered from hydrocephalus and interventricular hemorrhage resulting in brain damage. Physicians implanted a plastic tube in the brain which drained the excess fluids into the peritoneal cavity, a common procedure for the treatment of hydrocephalus and necessary to sustain life in such cases. Her parents were informed that the procedure was life-sustaining and had given their written consent for it. They nevertheless sued to recover damages "for the 'wrongful life' of the child and the cost of caring for her in the

state of total disability." The court rejected the parents' appeal:

The mistaken premise of this appeal is that allowing the child to die untreated was a legally viable alternative. It rests upon the report of plaintiffs' medical expert that intracerebral bleeding involving brain tissue on the 27th day of life was "ominous and bode(d) an extremely poor prognosis in terms of future intellectual and neurological functioning of the infant." But nothing in the record suggests that a doctor should have been able to foretell the full dramatic extent of Renee's eventual disability, and we find no support for the belief that a newborn child may be put to death through benign neglect on the mere expectation that she will, in some unquantified way, be a defective person. As the Supreme Court wrote in Berman v. Allen, 80 N.J. 421, 430, 404 A.2d 8 (1979), "it is life itself that is jealously safeguarded, not life in a perfect state."<sup>157</sup>

In the case of Thomas v. Atascadero Unified School District a California Court held that a school could not exclude or prevent a child from attending classes solely on the grounds that he posed a risk of transmission of the AIDS virus to his classmates or teachers.<sup>158</sup>

Ryan Thomas had become infected with the AIDS virus through a blood transfusion at Oakland Children's Hospital. The AIDS virus had led to pulmonary and middle ear problems and chronic lymphadenopathy. These were brought under control and physicians notified the school that no medical reason should justify his exclusion from school. It was noted that the AIDS virus is not transmitted through the

air but only through infected blood, semen, or vaginal fluids, and possibly mother's milk. Also, no case of transmission in a school setting had ever been documented.

On September 2, 1986, Ryan was permitted to attend school in a regular kindergarten class. Six days later Ryan was involved in a fight in which he bit another child without breaking the skin. The school informed the parents that Ryan would have to be kept at home because another bite would pose a significant risk.

A psychological evaluation was recommended. It was determined that Ryan's aggressive behavior was attributable to "his level of social and language skills and maturity...below those of his classmates." The psychologist could not "predict the form of future aggressive behavior," and recommended that Ryan be tutored at home.

The school district attempted to balance the interests of the family and those of the school and community. The district referred to the information published by the Centers for Disease Control pertaining to the education of children with the AIDS virus. Two of these recommendations are:

Decisions regarding the type of educational and care setting for HIV-III/LAV infected children should be based on the behavior, neurological development, and physical condition of the child and the expected type of interaction with others in that setting. These decisions are best made using the team approach including the child's physician, public

health personnel, the child's parent or guardian, and personnel associated with the proposed care or educational setting. In each case, risks and benefits to both the infected child and to others in the setting should be weighed...

...For the infected preschool-aged child and for some neurologically handicapped children who lack control of their body secretions or who display behavior, such as biting, and those children who have uncoverable, oozing lesions, a more restricted environment is advisable until more is known about transmission in these settings. Children infected with HILV-III/LAV should be cared for in settings that minimize exposure of other children to blood or body fluids.

The school district failed to present any further data or evidence that could prove that the AIDS virus could be transmitted by human bites. The court made the following conclusions of law:

1. The School District is a recipient of federal funds within the meaning of 29 U.S.C. 794, 504 of the Federal Rehabilitation Act of 1973.

2. Ryan Thomas qualifies as a "handicapped person" within the meaning of Section 504.

3. Ryan Thomas is "otherwise qualified" to attend a regular kindergarten class within the meaning of Section 504 of the Rehabilitation Act of 1973. The defendants failed to prove otherwise, and failed to prove that Ryan posed a significant risk of harm in the classroom setting.

4. Ryan was subjected to different treatment from other students at the school and he was excluded as a consequence of his "handicap."

5. Defendants did not comply with the criteria of 45 C.F.R. 88.4(b). It provides in relevant part: A recipient shall place a handicapped person in the regular educational environment created by the recipient unless it is demonstrated by the recipient that the education of the person in the regular

environment with the use of supplementary aids and services cannot be achieved satisfactorily.

The court noted that Ryan was handicapped under the meaning of Section 504: "one who has a physical or mental impairment which substantially limits one or more of his major life activities, as well as any person with a record of, or who is regarded as having, such an impairment."

The court granted a permanent injunction allowing Ryan to attend his regular classes and further awarded \$42,387.00 to his parents to cover attorneys' fees and costs.

In the case of Johnson v. Sullivan, a federal district court in Oklahoma held on June 22, 1987, that a denial of medical treatment based on disability or socio-economic status may violate the United States Constitution.<sup>159</sup> This highly significant case involves the non-treatment of children with spina bifida and represents a dilemma that has sparked world-wide debate over the past twenty-five years. Children born with spina bifida, (more specifically, myelomeningocele), present at birth with a protrusion of central nervous system tissues and fluids at a point along the spine. The protrusion may occur anywhere along the spine, but generally the higher up the lesion, the more severe the defect. The incidence of myelomeningocele varies with ethnic groups, the Irish having the highest incidence.

Those of African descent generally have a lower incidence. The range of occurrence is generally from six per thousand to one per thousand. Causes are described as multifactorial, there being some genetic and some environmental factors. A few teratogens have been found causative. Improved vitamin supplementation in early prenatal development may reduce risk in some individuals.

The treatment of myelomeningocele was for many years thought to be a futile effort. Although some physicians did close the backs of these infants, even hundreds of years ago, their prognosis was always poor. Surprisingly, some did survive. They were paraplegic and had no feeling in their lower limbs. Some would survive and live many years into adulthood with no treatment at all. Children with myelomeningocele usually suffer also from hydrocephalus or "water on the brain." In about 85 percent of cases, without relief from this condition the head swells, the brain deteriorates and the child does not live long. There have been exceptions from time to time, even cases of individuals living to adulthood with very large untreated heads and with intelligence sufficient to lead an independent life.

In the late 1950's, the first successful shunts, or tubes to drain the excess fluids in the head, were introduced. These were improved over the years with valves

and better materials. They were not without their problems and would frequently become infected, necessitating replacement. In any event, the birth of a child with myelomeningocele generally meant many years of burden to the family in the care and training of a disabled and often retarded child. Physicians, acting in their traditional role, usually did everything that was within their means and within the bounds of sound judgment to sustain life and facilitate procedures for promoting the comfort and well-being of these children.

As utilitarian considerations began to be expressed under the socialized medicine system of Great Britain and as British society contemplated the ever increasing cost of health care and the demands that a growing population of disabled individuals placed upon education, health care, social services and families, it was almost inevitable that physicians would respond and answer the call for relief. One such physician was Dr. John Lorber, Chief of Pediatrics at the Sheffield Children's Hospital. Dr. Lorber had been in the vanguard of aggressive treatment for children with myelomeningocele and had made significant contributions to the improvement of their care. He began, however, to advocate selection at birth for treatment of myelomeningocele based upon criteria designed to predict the quality

of life. Only those children who met these criteria (lower-level lesions, no other CNS involvement, no severe hydrocephalus, and no other anomalies) would be treated. If children did not meet these criteria, Dr. Lorber would write an order on their charts for high dosages of chloral hydrate (a tranquilizer) and water-on-demand. These children, drugged as they were, didn't demand anything. They simply dehydrated to death. They couldn't even produce enough tears to shut their eyelids.

Society in Great Britain does not often question the actions of physicians. Malpractice suits are rare, but when Drs. Gross, Cox, Pollay and Barnes of the Oklahoma Children's Memorial Hospital in Oklahoma City, Oklahoma, advocated the use of criteria similar to Dr. Lorber's, but with an even farther reaching social component, and reported that twenty-four children had died after hospital doctors recommended that no treatment be provided for them, the Spina Bifida Association of America and The Association for Persons with Severe Handicaps sued to enjoin the physicians from using their criteria to deny children needed treatment.<sup>160</sup> The criteria are described as "non-medical, social, and economic criteria--including projected intellectual capacity, degree of paraplegia, family wealth and resources, an geographical location." Damages were also sought by plaintiffs, including infants who were denied

beneficial medical treatment, infants who were evaluated, their parents and guardians.

Constitutional guarantees to due process and equal protection were allegedly denied. Federal prohibition of discrimination based on handicap by recipients of federal financial assistance, and federal statutes regulating experimentation on human subjects were allegedly violated. Damages for medical malpractice were also sought.

A "quality of life" formula was used by the Oklahoma physicians in making their decisions. It was denoted in terms of a formula, giving it a scientific appearance:  $QL = NEx(H+S)$ , QL being quality of life, NE being patient's natural endowment, physical and intellectual, H being the contribution of home and family and S being the contribution of society. "The nonmedical criteria thus included family wealth and resources, projected intellectual capacity, projected ability to walk, geographical location, and political and fiscal matters, such as alleged reduced government spending for medical care and school districts' purported inability to provide services for handicapped children. These criteria bore no relationship to the determination of whether the child would have benefited from medical treatment."

Using such non-medical criteria, treatment for babies could be quite different in spite of their identical

medical diagnosis. The plaintiffs alleged that these actions by a state-run hospital were without rational basis and violated the equal protection clause of the United States Constitution. They also claimed that the infants were deprived of a constitutional right to life and liberty without procedural safeguards. The parents were deprived of their constitutional right to the companionship, care, custody, and management of their children because they were not told of the criteria nor given time and information necessary for an informed decision regarding the treatment of their children according to their assertions.

The court refused the request of the hospital and doctors to dismiss the claims of the parents that their constitutional rights had been violated. Neither did the court dismiss the claim that the plaintiff advocacy groups had standing to sue and that a court order enjoining the hospital from continuing to engage in the discriminatory treatment of children could be sought.

Some of the claims of the plaintiffs were dismissed, namely claims for violations of Section 504 of the Rehabilitation Act of 1973 which prohibits discrimination based on physical disability. The court relied on United States v. University Hospital, State University of New York at Stony Brook<sup>161</sup> in which it was held that "when the intervention of a parental decision, well based on ade-

quate medical briefing or not, necessarily lies in the path of the infant's receipt of the benefit, it cannot be said either that the infant is otherwise qualified or that discrimination is solely because of handicap." Also dismissed were claims of human experimentation without safeguards and consent. The doctors were also held to have sovereign immunity as state employees. The plaintiffs are now appealing the dismissal of the Section 504 of the Rehabilitation Act claim.

Had the physicians who were parties to in this case never reported their work in a professional journal, the plaintiffs might never have gathered together to present their case. The fact is that such procedures are quite common throughout the United States. They are done discreetly and without public announcement. Physicians who treat neonates are constantly weighing in their minds the efficacy of interventions to preserve the lives of those with debilitating conditions. The trend is toward consideration for the demands or perceived needs of the parents rather than the best interests of the children. Dr. Lorber's criteria have been shown to be medically unsound. Like the criteria of Dr. Gross, et al., both medical and social factors determined the criteria. Dr. Lorber sought a medical solution to a social problem. Dr. Gross and his associates sought to openly define the social elements that

were just as much a part of Dr. Lorber's criteria. Dr. Lorber did not cease to treat all but the most promising of children with myelomeningocele because of any lack of medical feasibility, but rather as a method of dealing with the perceived burden upon society that these children posed.

## Conflicts Perceived by Parents Relative to the Rearing of Their Handicapped Children

How children are able to cope with their sickness or handicapping condition may often depend on how well their parents can cope with their afflictions. The behavior of parents is crucial to the way the child copes with his condition. <sup>162</sup>

When I heard about my son's illness, I took a crash course in Christianity, but it didn't help. <sup>163</sup>

The only thing I really wanted to do last night was will both of my children; I didn't think I could stand another minute of them. <sup>164</sup>

How parents react to their children's defects depends a great deal upon their own background and experiences with the handicapped and their feelings about themselves.

Clara was born in May, 1972, at home. As soon as I saw her I realized that something was very wrong. I could not believe my eyes. The features of my second child were those of a Mongol. My rejection was total and complete. I just did not want to know anything about her.

I thought that she was going to be a cabbage, burdening my husband and myself for the rest of our lives...we were going to have to live with a permanent child... <sup>165</sup>

A totally different approach may come when an otherwise healthy child is unexpectedly taken ill. The family of a twelve-year old on vacation noticed their son was becoming lethargic and miserable. They took him to a local doctor, thinking he might have some "flu." Within twenty-four hours they were told that he had leukemia. For this family the date of diagnosis became a special anniversary. There was Christmas, and birthday, and Diagnosis Day. Many parents reckon the child's life, not from his birthday, but from his day of diagnosis.

Another common experience at the time when parents are told of their child's condition is one of blotting out all other information after the initial revelation of their child's illness. Parents may hear one word, like blind, or tumor, and then not hear anything else for the next half hour.

One area of conflict between the family and society is that of the financial burden of caring for and rearing a handicapped child. With financial demands being greater because of the cost of caring for a child, there is an increased burden for the husband to earn more, or a resentment that the wife is unable to go back to work as soon as she might have liked to, or that she is totally unable to go back to work because she is caring for the child who needs constant attention at home. If the husband

works overtime, there is always the feeling, expressed or unexpressed, that he is escaping home difficulties by staying at work. Some fathers find that they must give up opportunities for advancement in their career because they fear that moving away from a trusted medical facility will be detrimental to the welfare of their children. A survey of parents of children with cystic fibrosis revealed that one-third of the fathers had given up opportunities for advancement in their careers because they wanted to stay near a hospital they trusted.<sup>166</sup> Families may still find it necessary to cease all social life once they have the responsibility of a sick or handicapped child in the home. They cannot find anyone who will babysit: "All our friends are frightened that something might happen." However, it may be the parents who are more frightened than any potential babysitter. The concern is very real to them. As long as a child is unable to walk, there is a lack of independence for the family. When a mother has a child who is growing large and heavy but is still not ambulatory, then the mother is reluctant to go where a lack of ambulation causes difficulty, either on public transportation or in a car where she would be required to lift the child into the car. Such problems are experienced by all parents with infants, but parents expect normal children to grow up and be able to care for themselves. The handicapped child

may remain like a baby, getting heavier and stronger all the time, and the chronically sick child, because of his dependence on medical care, remains his parents' responsibility.

The parent of a child with a life-threatening disease can never predict what will happen if everything in life continues just as it is at any moment. Parents feel that they cannot plan for a vacation with any certainty, and they cannot bear to contemplate the long-term future. It is often very emotionally traumatic, even heart-breaking, to hear a child who is likely to die within a year talk about what he is going to do when he grows up. A different set of questions is brought about by the child who does not have a life-threatening condition. The parents ask whether or not their child's children will also be affected. Will their child be able to have some degree of independence, live in a house on his own, get married, or take out life insurance? Will he become better or worse? At first, these questions may be asked by parents. When children reach adolescence, these questions are very important to them also. Another group of questions is aroused by those children who have a mental handicap as well as a physical handicap. One asks if they will ever learn to walk, or talk, or be able to go to an ordinary school. Will they be able to manage to work? Will they be able to get married or

have children? These questions can produce chronic anxiety in a family. They are constant and nagging questions. One anticipates that medical science will make some advances. Whether or not these advances will be able to help one's child is difficult to ascertain. Another question parents often ask: "What will happen to the child when we die?"

Not all parents express a feeling of isolation simply because they have a sacred handicapped child, but most report a feeling that they are being pushed towards isolation<sup>167</sup>. They are made to feel different, and they find that other families really do not understand or seem to want to understand what they are going through. The most common request sent to In Touch, a circular written for parents of the mentally handicapped, has been from parents who wish to be put in touch with others whose child has a condition similar to theirs. People's attitudes have contributed to this isolation. People generally have little experience in their daily lives with chronic sickness or severe handicap. They have no framework within which they might deal with these situations. Ignorance may lead to fear, and fear may form a powerful barrier. As one mother put it: "You would think cerebral palsy was catching the way people behave."<sup>168</sup> Some isolation may be the result of the behavior of the family itself. The energy required, both physically and emotionally, in caring for the sick or

handicapped child both by night and by day can be exhaustively taxing. There is less time, therefore, for establishing relationships with other people. The whole family may focus on the handicapped child, whereas before his coming there might have been many activities, such as athletics or entertainment or hobbies in which the family engaged. At a parents' discussion group one father was talking about his job and he was asked if he ever thought about his sick daughter during his working day. He paused and replied, "I never think about anything else."<sup>169</sup>

The element of guilt is difficult to define. Many professionals anticipate that parents will experience some degree of guilt either because of having produced a congenitally handicapped child or because of having been so negligent as to permit a child to become ill. Dr. Roith relates:

One psychiatrist states that if parents place their child in a hospital they will feel guilty because unconsciously this means that they are trying to get rid of him. Whereas another psychiatrist has maintained that if parents keep their child at home they will have guilt feelings because they are depriving it of the best medical and nursing care!

Landsdown has described four situations in which guilt is likely to occur.

1. When the child's condition is known to be inherited and the parents suspect that there is a risk but do nothing to find out more.

My first reaction on being told was to remember that my mother had told me that two cousins had died of it, and I blamed myself for not thinking of it.

2. When mothers have continued to smoke, drink heavily, or take drugs during pregnancy.
3. When parents have delayed seeking medical help at the first indication of abnormal behavior.
4. When parents feel that they are not doing the utmost possible for the child, either by obtaining the best medical care or by insuring that social education provisions are as perfect as can be.<sup>171</sup>

Parents may find themselves subject to increased feelings of revulsion or anger or a feeling that life is just all too much. It may be a reaction to a specific situation or to a series of situations which wells up and threatens to become uncontrollable. One mother, who had lost two boys, was told that her third child was mentally handicapped.<sup>172</sup> Many situations are understandably beyond the ability of an individual or a couple to cope with. Such a case was that of the unmarried mother of two boys under

five, both handicapped, neither of whom would ever be able to walk.<sup>173</sup> One mother of a child born with an ugly blemish over her left eye was abandoned by her husband the day the girl was born.<sup>174</sup> These are the parents who are revolted by their children's inadequacies and are sometimes incapable of carrying on for another hour. These are not "unnatural" feelings as one might imagine. They are common, biologically normal, and have to be faced.

Parents must also deal with the limited understanding of their neighbors and friends. "How can you possibly punish him? He has cancer." Some parents may indeed find it impossible to discipline a sick or handicapped child as they do one who is normal. This may result in very unhappy little boys and girls who do not enjoy a life in which they always get their own way, who have tantrums when others thwart them, and who receive the message that even in naughtiness they are different from other children. Some parents may have deeply rooted feelings of which they are themselves not fully aware and which make them want to keep the child a baby, for it is acceptable to have a totally dependent baby and so it feels more comfortable to pretend that there is nothing wrong with the child, that he is just still very young.

The problem of denying the illness may be a cause of conflict between the family and those outside. Some

families do, from time to time, play with the idea that there is really nothing wrong with their child. These are the parents of children who, for long periods of time seem to be quite well. They look healthy, run around with friends, eat and sleep well, and get on well at school. At times like this some parents even stop the child's treatment. They usually start again quickly when the child suffers a relapse. Some families will accept a physical diagnosis but stubbornly refuse to believe what they are told about a child's mental state. No matter how many tests are given they always find an excuse: the child is shy, doesn't like hospitals or clinics, has a cold, had a cold last week, is lazy, playing everyone up. Sooner or later they have to come to terms with the extent of the handicap and this can be very difficult for them to accept.

Another situation of conflict arises with brothers and sisters. By the time they are eleven years old, five of every six children have a brother or sister. Nearly all children who have siblings spend more time with them than they do with their father, and once they are ten, they see more of their siblings than they do of their mother.<sup>175</sup> In the last few years there has been a gradual accumulation of knowledge about the sibling of sick and handicapped children. Most of it has come from interviews with their parents.<sup>176</sup> The birth of a normal brother or sister in a

normal family can make the handicapped child feel jealousy and revert to a much younger behavior. Some children start to wet the bed again, or demand to be fed from a bottle, or even stop talking. One study of a series of children suggested that over half were disturbed, to some extent, by the arrival of another child.<sup>177</sup> It is not surprising then, that the birth of a handicapped child, or one who is clearly sick, or the development of an illness in an otherwise healthy child, can lead to problems. As the family balance is shifted, jealousy can develop in the normal child. Landsdown points out a number of influences that the handicapped child may have on siblings:

1. Children who are younger than the patient are generally more vulnerable than those who are older. This is probably because the attention often given to younger, healthy children is diverted to the handicapped child.
2. Girls are more vulnerable than boys, perhaps because they are seen as substitute mothers.
3. The siblings of the handicapped child whose condition is inherited or life-threatening, who has, for example, muscular dystrophy, are more powerfully affected than are the siblings of a child having a chronic, non-fatal

condition like cerebral palsy. Children fear that they, or their children, might develop muscular dystrophy, and they are often given far too little information to help them to allay such fears.

4. A major problem develops when one child has a degenerative condition and then a sibling develops the same condition and can anticipate what will happen to him. Margaret Atkin, a social worker who has helped many such families, quotes John Dryden to illustrate this point:

With unerring doom.

He sees what is, and was, and what is to come.<sup>178</sup>

5. There is no characteristic disorder evident in siblings, but attention-seeking behavior, jealousy, and regression to an earlier stage can all be expected.<sup>171</sup>

### Fear

The element of fear is a significant attribute of the conflict parents have with society over the rearing of their handicapped children. Parents may feel rejected by

society as a whole or by social and professional groups. The professional community or the community in general may have fears related to the integration of the handicapped into their environment. Fear is one of many parents' first responses to the birth of a handicapped child. They may fear that they are unable to cope with the difficulties of rearing a handicapped child. They may be apprehensive and fearful of the changes that the presence of a handicapped child in the family will bring about. As the years pass, the nature of parental fear may change in content, in quality, and in intensity, but because of the uncertainty with which a family with a handicapped child must always live, there will always be a certain degree of fear. Parents agonize about their own limitations and about the restrictions that their handicapped child will impose upon them. Parents are fearful of the world's responses to their child's manifestation of limited skills and methods, abnormal appearance and comprehension different from the expected response to the child without a handicap. They worry about their child's future, about themselves, and about the siblings. The siblings themselves may also express fear and anxiety about the part the handicapped child will take in their lives and in the life of the family as a whole. The mother of a child with spina bifida, for example, trembles when she contemplates her daughter's

adolescence and adulthood.<sup>115</sup> Her daughter is four now. She cannot walk by herself, although she is learning to get around with a walker. The mother believes that the worst problems will come later. "People tell me things will get better, but I don't see how they can." She dreads the inevitable decisions. "Ought my daughter to go to the local public school?" for example, or "Would she thrive better in a special setting?" The mother knows that as the years pass the child will grow more conscious of her own differences. "Right now it's mainly I who feel it," the mother has told the mother's group, "but as she gets older, I'm worried whether kids will tease her, and how she'll feel when they run off to play and she can't. Right now, they'll run off, and she's left sitting by herself in the corner. I feel sad for her, but she doesn't seem to notice." Parents of the more severely handicapped children, the profoundly retarded, the autistic, and those with multiple disabilities may face a different set of issues. When lifelong dependence seems inevitable, the prospect of institutionalization darkens the horizon. One mother said,

Sometimes I think I will die from hurting to think of his future without us, for now he has love, good health, happy times, and lots of work (therapy) to do. What does he have to look forward to if he cannot improve, a bed with bad smells and only a dimness of life around him?"<sup>115</sup>

Josh Greenfield, whose son, Noah, is autistic, talks to another parent about what lay ahead. After surveying the possibilities, they agreed: "Most of us, for all our hopes and dreams, are still fattening up our children for the inevitable institutional kill."<sup>179</sup> In her book about her son who suffered from hemophilia, Susan Massie describes her fears:

There is nothing to do but learn to live with fear in constant dread of the unknown. Such a way of life does strange things to the personality. Fear can grip and dominate you until you are unable to move in any direction. A person living with hemophilia can finally become paralyzed with fright, like a rat in a maze who is met with an electric shock at every innocent looking exit, until finally he simply turns frantically in circles, afraid to try any more doors...<sup>180</sup>

Parents fear for themselves, for the prospect of growing old, declining in strength and even dying. The parent of normal, healthy children anticipates a natural cycle of growing up and leaving home. Children who require an extraordinary expenditure of energy and may exhaust the physical strength of their parents will nonetheless grow older and demand less as their parents also grow older. A child's severe disability disrupts the natural cycle and the child may remain dependent beyond the parents' strength, or health, or lifetime. Parents may have to contemplate their old age long before they would otherwise do so. Helen Featherstone, in her book about her retarded son, recalls:

I remember, during the early months of Jody's life, the anguish with which I contemplated the distant future. Jody cried constantly, not irritable, hungry cries, but heart-rending shrieks of pain. Vain efforts to comfort him filled my nights and days. One evening when nothing seemed to help, I went outside intending to escape his misery for a moment, hoping that without me he might finally fall asleep. Walking in the summer darkness I imagined myself at seventy, bent and wrinkled, hobbling up the stairs to minister to Jody, now over 40, but still crying and helpless. Parents' thoughts linger on. The costs--human, as well as monetary, of raising such a child, and on the probability that they will ultimately fail to provide what he needs. <sup>113</sup>

Parents may have difficulty dealing with their own fear regarding their capacity to even love their child or face the reality of their child's likely future. Greenburg, in his account, relates an interesting story regarding the reality of his son's schooling:

We visited the nearby school for retardates, a red brick building set on the side of a hill, like a bunker. There is little space. In a railroad-flat setup, they have three classes: younger children, older children, and adult retardates. The classes for the children look like happy bedlams, mongoloids running around, kids screaming, their muscles twitching. We came in time to watch one of the adult retardates celebrate his birthday. The singing of "Happy Birthday", the blowing out of candles, the serving of the ice cream and cake. Of course, they were all like children. Those close-eyed, sweetly vacuous heads. I almost cried. I refused to imagine that Noah, my <sup>181</sup>son, belonged in such a place with such a group.

The parent in such an encounter may find himself recoiling from the retarded children and wondering whether

he will be able to care for his own child when his child is older, like those he sees.

Fear is also generated unnecessarily by friends and professionals who want to persuade parents to believe particular things or behave in certain ways. Those who believe that institutionalization serves the best interests of parents and children often paint an excessively pessimistic picture of a disabled child's prospects. In Helen Brown's book, Yesterday's Child, she describes how her doctor urged her to give up her infant daughter, asserting that "this child will be a vegetable. If you spend the rest of your life taking care of her, she'll never recognize you."<sup>182</sup> Her neurologist, who encouraged the Browns to take Karen home, assured them that she would be handicapped only by a slight limp. Both the pediatrician and the neurologist were incorrect. Professionals and friends and relatives who tell their frightful tales do so in good faith. In many cases they hope to persuade conscientious parents to institutionalize their children, and they choose an argument designed to diminish parental guilt. They see institutionalization as a necessary step for the good of those whom they care for. If the parents do place their child in an institution, a dark view of the child's developmental potential may help reconcile them to a difficult choice. Parental fears can be debilitating.

Those who attempt to dispell these fears often fail because the fears are so firmly grounded in reality. The parents' grim image of available residential care, for example, often reflects reality only too accurately. Some parents respond with resentment toward the bleak picture painted by many professionals who fail to show them that the future need not be so bleak as it has been pictured. Claire and Joseph Canning, whose daughter Martha has Down's Syndrome, believed that their grief would have been more bearable "if just one person had come to us to tell us that despite our sadness there was hope, that this was not the end of the world, but rather a challenge."<sup>183</sup> Grandparents of the handicapped child can be especially difficult for the parents to deal with. One instance of this difficulty is the experience Betty Piper had with her mother-in-law and father-in-law and even with her own mother:

I remember the tears of my father-in-law and the reluctance of my mother-in-law to visit me in the hospital when Jeff was born. I remember the hurt and the anger I felt as my mother rattled on about what she and a friend had had for dinner the night before and how hot and humid it was in the hospital. She talked about going to the beach, while all I could think about was whether our baby would live.

I was shocked when my mother-in-law demanded to know 'who signed for that baby's operation'. Ignoring my bewildered silence she pressed on with unconcealed hostility. "Someone had to sign." Then I finally dredged up. "I guess Carl did. I don't remember who did..."

<sup>184</sup>"You have burdened my son for life." she said.

These conflicts between the parents of handicapped children and their own parents are understandable in the context of the grandparents' point of view. Having had more experience in life, they see the birth of a handicapped child from the larger perspective of the effect that this child will have on the total family. They see how radically a child's defect will alter family life. The mother and father of a handicapped child have an unqualified need for comfort and understanding as they cope with their confusion and disappointment. It is understandable that they may become infuriated when their own parents withdraw to mourn, or worse, strike out at them in anger. But the grandparents have also lost what they had hoped for in a normal grandchild. The retarded child, as he grows older, may present more problems for his siblings as they attempt to handle other children's assessment of the retardation. One mother describes a conversation she had with the siblings of her retarded son:

One day after school Chris confronted me. There was a white line around his mouth. He suddenly looked very small and vulnerable for eight years old.

"Mom," he asked, "what is a vegetable?"

I knew immediately what was coming. In spite of my intentions to always give honest answers, I heard myself stalling. Vegetable? Oh, you know, peas, carrots...

"No, not that kind! You know what I mean. The kids on the bus said my brother is a vegetable."

"It's just a word." Suzanne, then ten years old, broke in. "It's a word some of the kids use when they

want to hurt you or be mean and nasty. Like dumb-dumb, rattle-brain and...." she swallowed, "retard."

"Do the kids say things like that?" I wished I hadn't asked. Their faces told the whole story. <sup>185</sup>

When a community is supportive of the family of a handicapped child, they expect a certain standard of behavior on the part of the family. Lucy Forrest described to a mothers group the ways that neighbors and strangers had helped her and her husband Kevin to implement a demanding treatment plan for Christopher:

Volunteers came in daily to pattern the little boy: contributions helped the family finance bi-monthly trips to a distant clinic, but this support, given freely during the early months when the Forrests devoted every minute to their baby, almost evaporated when they started to pick up the threads of their previous life, specifically when Lucy began to repaper their new house. Some of the volunteers acted shocked and even hostile. Their reaction wounded the young couple; they felt that the world exacted a heavy price for its sympathy, asking that they devote their entire <sup>186</sup> lives and give up pleasures others take for granted.

The Forrests' experience points to parallel perils on a larger scale. When the families of handicapped children accept organized public assistance, providers of services for disabled children may elicit significant anger and bitterness from the children's parents and cause heartache for the whole family. Although families of severely impaired children had in the past little hope of assistance from the public sector, and parents without the financial capacity had to depend on luck and charity to meet their

child's needs, services have improved in recent years. Federal laws now guarantee appropriate education for all children, regardless of their disability. Nonetheless, parents and children in many areas continue to require services that are either unavailable or else available only in a form that mocks the humanity of those needing the services. The quality of residential facilities for the retarded hurts parents deeply and demonstrates how little the larger society values these children. This hurt can turn to anger. Of all the sources of conflict and targets of parental anger, the medical profession is usually the first to be named. Parents express anger about the manner in which their doctor or doctors present the initial diagnosis. According to Janet Bennett, "Hardly anyone is pleased with the way they find out about their child's handicap."<sup>187</sup> The parents complain about the doctor's reluctance to believe them and to respect their burning desire to know what is really wrong. Parents complain about cowardice and equivocation. They complain that doctors swing from one infuriatingly unrealistic extreme to the other. They complain that hospital staffs treat them without tact, consideration, or even common humanity.

Robert and Susan Massie took their infant son to a major hospital to learn why he had continued to bleed after a routine test.

The hospital personnel treated us with that blend of condescension and coldness that I have now learned to know well and to hate. They took Bobby away. No one would explain what was going to be done to him. Mysteriously, they said only, "We are going to take some blood." He was taken from my arms, my roly-poly, jolly baby, and rolled away down the hall. Then, chillingly, I heard from far down that hall the terrible screams. I was filled with panic. The screaming went on and on. We asked what was happening. "They must not be finished yet," was the curt answer. After nearly an hour, I was so agitated that Bob said, "I'm taking you downstairs so you won't have to hear it anymore." We went to the cafeteria. When I came up I could still hear his screams; by now they were hoarse. Beside myself, ignoring the nurses who called after me, "you can't go down there," I ran down the hall in the direction of the noise and into a room with other babies and cribs. I found Bobby, still screaming, exhausted from crying so long. He was all alone. I snatched him up, rocked him, and kissed him. In a few moments his crying stopped. I found out later that the procedure itself had taken only ten minutes. They had taken blood from the jugular vein and dumped him back in his crib, leaving him to cry, although we had been only a few yards down the hall and could have calmed him quickly. It was the first of many such experiences. In the years ahead I was seared by the lack of understanding, by the lack of compassion, yes, the cruelty--the cruelty, that comes from the rigid and arbitrary rules practiced in some of the best hospitals we have.

... (The doctor's) eyes looked down at the floor as he hurriedly came in. There were no preliminaries. He announced coldly and matter-of-factly, "The child has classical hemophilia. There

will be compensations, you may be sure." And with these enigmatic words, he turned on his heel and walked out.<sup>188</sup>

### Anger, Pain and Loneliness

When parents do not know the diagnosis of their child's illness they may be frightened. They may be vulnerable. They have already suffered days, or perhaps even months or even years, of doubt and searching from physician to physician. They may stand exposed and powerless before the experts. Indifference, condescension, and equivocation wound them deeply.

Parents may experience anger that is beyond what they themselves feel is appropriate for the damage that they are subjected to. An example is that of a mother who, upon learning that her child had toxoplasmosis, expressed anger towards her physician when he reassured her that her future children would be free from infection. "I knew he was pointing out one of the few bright spots in a darkening sky, but I had not asked about my childbearing future. I remember thinking angrily, 'I don't care about future children.' I love this baby. Don't dismiss him as though someone else could replace him."

Helen Featherstone offers an interesting explanation of parental anger and the direction it could constructively take:

Parents' anger, when expressed clearly and forcefully, can help keep professionals honest and teach them the limits of acceptable behavior. Some doctors apologize and change their ways when they learn they have hurt a child or a family. Even when discussion brings no resolution, the parent who complains appropriately avoids the curdled taste of undigested anger. However, doctors command more respect than parents, both in the agencies serving the disabled and in the world at large. This great disparity in power shapes the relationship of physician to parent and reduces the likelihood of honest exchange. Many parents see the inwardly or complain to friends but avoid confrontations with the professionals themselves. These mothers and fathers worry about losing services or acquiring a disparaging label. Their fears reflect reality all too well. Organizations sometimes take criticism as evidence of a parent's emotional disturbance.<sup>189</sup>

### Siblings Perceptions

The siblings of handicapped children stand with one foot in the world of normal individuals and the other in the world of their exceptional family. Ordinary children will sometimes treat a handicapped child cruelly and associate his siblings with the handicapped child. The sibling may be forced to mediate, to explain, and sometimes to choose between conflicting loyalties. This can make him angry with the "normal" world, with his disabled sibling, and with himself. A young college student whose brother

suffers from severe hearing loss and deformities of both arms described an incident he had experienced:

This summer I worked at a playground. One day a bunch of kids and I were playing. Everybody stands in a circle and throws a ball to one another. And all of a sudden these little kids started dropping away from the circle. I was playing with them so I did not really pay much attention to why some kids were dropping out. It's just slowly getting more and more quiet and I turned around: my brother was standing there. Of course, this is summertime, he has short sleeves on and these kids, even now I'm tempted to say these little creeps, it really upsets me--they made a circle around my brother, just made a circle around him and started looking at him, and I just did not know what to do. On the one hand I felt like saying, and it upsets me now to think that I would say what I wanted to say, "Get up and get out of here." Even now that I say it, it is totally disgusting and at the same time I wanted to say to all those little kids, "If you don't move now I'm going to throw you all over the fence." Even now I have not resolved it--more than anything else it shows me that I have not really come to terms with the whole thing. Furthermore, it gives me some appreciation for what my brother has to go through. He has to go everywhere. 190

### Reflections on the Family Process with a Handicapped Child

There are conflicts which arise between parents and the professionals who serve them and their handicapped children. By virtue of the situation itself, some of these conflicts are unintentional, but they arise out of the process in which both parents and professionals deal with the child's difficulties. Parents, at the time of their

child's diagnosis, have a great need for information. At the most basic level, they need a labeling of the difficulty. They also want to know as much as possible about the origin or etiology of his disability and what it's going to mean for their child's life. Some of these questions cannot be answered right away, and the resultant uncertainties can be a source of further conflict. Parents will often suspect a difficulty before anyone else, but the official diagnosis comes from a professional, or perhaps from a school. Physicians play an important role in the life of most children or families. They see the child at birth, for immunizations and checkups, and parents most frequently will discuss their concerns about their child with their physician before they consult another professional. Parents, however, frequently complain that physicians fail to respond candidly to their concerns.

The clinical picture the child presents is often a confusing one, and the physician shares the parent's uncertainties. Sometimes a wait-and-see attitude is appropriate. But some doctors will postpone actually confronting parents with an unpleasant reality even when the problem is obvious and apparent. In a study of twenty children with Thalidomide deformities, Ethel Roskis reports that the doctor in the delivery room assured more than half of the mothers of their children's normality.<sup>191</sup> Consider-

ing the obvious nature of these children's deformities, one must assume that some of the obstetricians consciously deceived the mothers. When the diagnosis is not clear, as is typical in the case of slow development or minimal brain damage, parents and physicians sometimes collaberate unconsciously, minimizing the significance of the problems:

Thus, until this point, we had essentially denied to ourselves the existence of a problem serious enough to require seeking help for it. We had built up a fine rationale for explaining Joan to ourselves. Her prematurity, her individual rate of development, a probable immaturity of her nervous system, and frustration based on lack of language were some of the alibis that lulled us into inactivity.

We plodded on with the eager anticipation and fervent hope that each new day would release some words we hoped lay merely dormant within Joan. This expectation remained unfulfilled. The days continued to be long and miserable. They varied only in that some were more intolerable than others. None were good.<sup>192</sup>

Reassurances can immobilize some parents, even when they apparently appreciate it. The parents of a boy with Down's Syndrome waited six months before hearing of their son's handicap. The mother later suspected that the doctor had attempted to test her own readiness for diagnostic information by remarking on the baby's brightness at the three-month checkup. The effort backfired: instead of talking about her worries, the mother clutched at the

encouraging comment "as a drowning man would at a straw."<sup>193</sup>

Physicians may hesitate to confront parents with the truth when they so "greedily devour little morsels of assurances." When a physician finally does offer a diagnosis, after weaving his way through the intricacies of a confusing clinical problem, he may not have met entirely a parent's need for information. Parents do not always understand the diagnosis at first. The interviews may be brief. They may be in shock having heard their child labeled, even if they themselves noted the problem previously and asked for a diagnosis. They may not think clearly, or listen, or ask appropriate questions. Medical jargon may also be a hindrance to good communication. Parents often declare that they do not understand what went on in their interview with their physician. Professionals often use language designed to protect their patients from unpleasant stereotypes and in the process cause them to miss the point altogether. One mother reports her encouragement when the doctors summed up her child's problems with the phrase "delayed development." To her the word delayed suggested that her child was now slow, but would catch up later. She thought of a train that was delayed: it is late, but eventually it does arrive. She

realized later the bleak truth. "That's not what it meant at all. It means that she is a retarded child."<sup>194</sup>

Some professionals who are undecided about the benefits of an early diagnosis may feel that "a few more good years" may be helpful. Usually parents know that something is amiss with their child, and they may incubate fantasies which undermine their happiness as effectively as the truth would. They may be more reassured by a convincing diagnosis. Most parents are eager to find out more about the causes as well as the cures of their child's problem. Sometimes this aggressive curiosity is upsetting to some professionals. They worry that further knowledge might provoke more self-reproach. The professional often responds that the treatment of the condition is more important than its origin. But parents who do not know the cause of their child's disability may torture themselves in all sorts of ways. They may fear that they are not capable of bearing normal children. A truth which is difficult to bear can often rescue a parent from self-destructive fantasies. In the case of the Thalidomide babies, Ethel Roskis found that twenty mothers felt greatly relieved when they learned that a drug they had taken during pregnancy had caused the deformities. They had presumably suspected something even worse.<sup>191</sup> Professionals who withhold information or evade questions imply that they doubt the good sense of the parents. When they discuss the child's problems candidly,

they convey respect. Kelley, et al., report that one mother said, "In a sense we do become experts on our children. And it really helps to know that somebody in the professional world thinks that you're intelligent and that you can handle the information, whatever it happens to be."<sup>195</sup>

## PARENT-SCHOOL CONFLICTS

Parents of children in special educational programs have frequently been in conflict with schools. They have fought hard to obtain appropriate services for their children and they have fought equally hard at times to get their children out of special education programs when they have felt that these programs were not in the best interest of their children.

Parents of minority handicapped children have often been faced with the double problem of finding appropriate educational services and dealing with discrimination in the schools. Two landmark cases, Diana v. State Board of Education (1970) and Larry P. v. Wilson Riles (1971), both brought in the state of California, dealt with the disproportionately high minority enrollments in programs for the educable mentally retarded.<sup>196,197</sup> These cases were decided in favor of the parents and caused dramatic changes in educational programming and the way educators go about identifying EMR children. Public law 94-142, passed in 1975, incorporated many of the points made by plaintiffs in these cases. Nondiscriminatory assessment, placement into the least restrictive environment, and the assurance of due

process and parental participation were issues brought up in these cases which 94-142 was designed to address.

The problem of racial segregation was one of the primary reasons behind the abolishment of self-contained classes for EMR children.<sup>198</sup> The mandate in the Diana case directly affected EMR enrollments in California. Between 1969 and 1980, enrollments decreased from 55,519 to 19,370. The correction of the disproportionately high minority enrollments was only slightly facilitated. Black student enrollment in EMR declined from 27.1% to 23.2% and Hispanic enrollment decreased from 28.2% to 22.6% in this time frame.<sup>199</sup> In 1982 it was found that 17.5% of the children classified as mentally retarded in California schools were Black even though Blacks constitute only 9-10% of the school population. This discrepancy was not found for other ethnic minority groups.

In 1983 the U.S. Department of Education reported that the number of children classified as mentally retarded in the schools had declined by 33% since 1976.<sup>200</sup> Projections based on an Office for Civil Rights survey in 1978 estimated that 3.46% of Black children were classified as EMR while only .98% of Hispanic children and 1.07% of White children had received that designation. In New Jersey 17.8% of the total school population was Black, but 43% of the children designated as EMR in that state in 1983 were

Black. In Ohio it was found that for every White child in an EMR program there were 3 Black children enrolled.<sup>201</sup>

Even when EMR children are "mainstreamed" they are often educated in racially segregated settings. It has been noted that little in America has changed for Black children in the public schools since the 1954 Brown v. Board of Education case. Kenneth Clark noted that most Black children "are still required by various evasive devices to attend racially segregated and inferior schools."<sup>202</sup> In 1980 15% of all Black children in California attended schools with 90-100% Black enrollments. Schools with predominantly minority enrollments were attended by 61% of the minority children in the state, an 87% increase since 1968 in the number of minority children attending schools with 50% or more minority children. "The degree of isolation has become critical, with 43% of all Hispanic students and 43% of all Black students attending segregated schools."<sup>203</sup>

The problem of reverse discrimination was noted by MacMillan and Meyers.<sup>204</sup> Part of the mandates handed down in California subsequent to the Diana case included quotas for ethnic representation in EMR classes proportional to total enrollment in the school district. When a school district was "at quota" for minority children in EMR programs, and a regular classroom teacher encountered a child with a severe academic problem, a recommendation was

made to the parents for an educational assessment for possible special education placement only if the child was Caucasian. Thus services may not be provided to minority children in need of them for fear of upsetting the quota.

Parents applied to the courts for relief when they felt that their children were being discriminated against by being classified as mentally retarded. It was felt that these children's low scores on intelligence tests were the result of cultural bias and reflected lack of opportunity for these children. In reaction, educators, fearful of being labeled segregationists, accommodated these children with IQs between 70 and 90 in the regular educational programs and simply tolerated their nonachievement.<sup>205</sup>

Learning disability programs could not touch these children because, in order to accommodate a child into an LD program, there must be a marked discrepancy between achievement and IQ. The lowest IQ band which would permit a severe discrepancy to be established averaged 82.7. According to Forness, "It is therefore quite possible that children with IQs in that general range might never qualify as LD, no matter how low they score on achievement measures."<sup>206</sup>

The basic concern of MacMillan et al. expressed in their examination of the impact of the Diana and Larry P. cases on educational provisions for minority children is that

large number of lower socioeconomic status minority children are denied adequate education:

regardless of what they are called or where they are taught...With the press for excellence coupled with the lack of substantive instructional improvement for low SES children with chronic achievement problems, we conclude that appropriate instruction for these children is as elusive today as it was in the late 1960s. <sup>207</sup>

The reasons for children to leave special education programs were examined in a two year follow-up study by Walker, et al. <sup>208</sup> Parents of 1,829 children in special educational programs were interviewed and asked to rate their satisfaction with their child's overall educational program. Apparently, how the parents felt about their children's education did not significantly affect their staying in a special education program. Those most frequently terminated from special education and completely mainstreamed were those whose problems could most easily be dealt with and for whom maturation had a most significant effect. Of those originally classified as speech impaired only 46% remained after two years. Thirty-three percent were terminated and 21% were reclassified. There were higher termination rates for children in grades four through six which, the authors suggest, may be the result of a lack of services after elementary school. The learning disabled and behaviorally or emotionally disturbed were the next most likely to be terminated or reclassified. Very few

of the children in programs for the mentally retarded, visually impaired, or physically or mentally handicapped were terminated from special education. The authors felt that this "reflects the permanency of their problems: for example, a mentally retarded child does not 'get better' through treatment or maturation."

A shift was noted from physical or multiple impairments to mental retardation, but far greater than this was a pattern of reclassification of children whose parents' independent report of the child's major problem did not correlate with the school's assessment. The authors could not determine with certainty, but suggested that the lack of congruence may stem from:

the parent's inability to communicate at an IEP (individualized educational planning session), the school's nominal preference for a category that may not perfectly characterize the child's problem, or the school's inability to communicate clearly to the parent what precisely is wrong with the child. 208

## CONFLICTS BETWEEN PARENTS AND SOCIETY IN ETHICAL DECISION- MAKING

### Euthanasia and the Handicapped Newborn

According to Dennis J. Horran and Steven R. Valentine, infanticide of handicapped newborn infants, either through neglect or by direct intervention, has become a common practice in hospitals across the United States.<sup>209</sup> Recent advances in prenatal diagnosis enable physicians to detect the presence of many genetic defects during pregnancy. They are consequently also enabled to eliminate a handicapped child before birth through abortion. There is, however, an increasing incidence of the killing of handicapped children after birth. Horran and Valentine contend that the practice of destroying unborn handicapped infants, often referred to as eugenic abortion, will increase as screening programs for pregnant women also increase. American law appears to be quite contradictory in its treatment of infanticide and eugenic abortion. Either through neglect, omission, or by direct act, infanticide is illegal and punishable under both criminal and civil law. Eugenic abortion, however, like all abortion, was made legal as a matter of

constitutional law by the Supreme Court's decision in Roe v. Wade.<sup>210</sup> There has ensued in American courts a proliferation of so-called "wrongful birth" actions wherein parents claim that, "...but for the failure of a physician to detect handicaps in prenatal diagnosis, the child born with defects would have been aborted." These actions place the physician in a defensive position. In order to protect himself he must employ the latest technique of comprehensive prenatal screening for genetic defects and, should the mother so desire, perform or arrange for another to perform a eugenic abortion. He may be liable for massive damage awards to parents who claim that such a fetus would have been aborted had the doctor conducted the relevant prenatal screening. Thus, the physician who abandons the handicapped child that it might die is required by law to conduct what some have labeled "a search and destroy mission" against the handicapped child which is unborn. Professor John A. Robertson, who has made possibly the most comprehensive legal analysis of withholding care from the defective newborn, comments on the Duff and Campbell paper from the New England Journal of Medicine.<sup>211, 212</sup> Robertson points out how surprising it is that, under these circumstances, physicians fail to inform the family of the rights and obligations associated with these problems, and the legal ramifications of considering

death as a possible solution to the problem presented by the handicapped newborn because the child born is a person under the law. Indeed, any decision regarding the welfare of the child presupposes the child's constitutional rights. No matter how defective, such children have the same rights under criminal law and under the Constitution that anyone else might have. These simple truths are seldom communicated to the parents who must share the burden of reaching a decision. One might even argue that the handicapped child has more rights because of his dependent, and possibly retarded and immature status, and consequently has a stronger moral claim upon parents and society than a healthy child would have. The hospital, the parents, and the physician are all responsible for meeting their obligation to care for the child. Although it may seem to some to be morally sensitive to respect the final decision of the parents or to respect the decision of the parents as final, the parental decision to withhold future treatment will neither insulate nor protect the physician or the hospital or its personnel from a potential liability suit, either civil or criminal. Considering such a case, one must first determine whether the child in question is treatable or non-treatable. If there is no treatment for the condition, then the fact that no treatment is given should not bring about the condemnation of those who pursue a

course of non-treatment for the child. Such cases as multiple congenital anomalies that add up to a hopeless case with a prognosis that offers no prospect for recovery or relief through treatment do not bring into operation either civil or criminal sanctions of the law. Withholding treatment in such cases would be considered sound medical judgment, based only on medical factors and not social factors. When treatment is useless the physician cannot be mandated to treat. In treatable cases where the prognosis is or may be guarded, but where an acceptable form of medical intervention that can correct the condition of ill-being that otherwise would cause death is available to the physician, then to neglect such a child would be murder if the child dies. Professor Robertson finds potential liability for the parents as a result of such an omission or such a decision, and sees all the conditions being met for homicide by omission. First, the omission of a legal duty to protect another, which the parent has to the child; second, a willful or knowing failure to act, with knowledge of the potential result--withdrawal of treatment, which will result in death; and third, the failure or omission as the probable cause of the child's death. If the omission is intentional, the consequences might be a first or second degree murder charge. If the omission is careless or negligent (that is, if the state of mind of the people

participating in the decision-making process is such that they are not capable of making a rational decision) it could be classified as gross negligence, the charge being involuntary manslaughter. The problem for the physician commences when the parents make a decision adverse to treatment. The physician and the hospital have a duty to the child which arises out of the contractual relationship they have with the parents of the child. A physician and hospital agree to render medical services, and the parents agree to pay for them. The physician's obligation is to ensure the medical welfare of the child as long as the child is in the care of the physician or the hospital. If the parents refuse treatment, the physician has the option of withdrawing from the case so that the family may remove the child from the hospital. This does not relieve the professional from an obligation to report the neglect or abuse of the child. He must struggle then with the problem of whether, even if the child is withdrawn from the hospital, he should inform the authorities that the child will not receive proper medical treatment. The hospital may seek the court's help in the appointment of a guardian who can then consent to the treatment on behalf of the child. Tort law or personal injury law may also be applicable in these cases. A failure to treat can amount to the commission of a willful or intentional tort, or a negligent

omission, or abandonment of a child.<sup>209</sup> The physician and the hospital are not protected simply because the parents have consented to the withdrawal of treatment. When sued by someone on the child's behalf for not having rendered treatment, which failure to treat resulted in the child's death, the hospital could come into court and say, "The parents couldn't give us consent." If a child remains physically in the custody of the hospital in one of its rooms, and, therefore, under the care and treatment of one of its physicians, there is a responsibility that must be exercised. If parents objected to treatment or if parents consented to withholding treatment it would only mean that the parents would be barred from gaining from the action. Should a child die in such a case, there would be a legitimate cause for action, namely a wrongful death. In the case of a death of a small child and a court action for wrongful death, the law often presumes pecuniary damages. Such money, if any, would not go to parents who consented to withholding of treatment. They would be barred from such recovery by virtue of their own consent. However, other family members who did not participate in the withholding of consent could bring such action, and, indeed, if all family members withheld their consent, then a public guardian could bring such an action.<sup>213</sup>

It is imperative that the physician act as a physician using sound medical judgment rather than as a determiner of social well-being. According to Gustafson, the norm for treatment in such cases should be the same for the child with atresia in Down syndrome as for the child with atresia who is normal and healthy.<sup>214</sup> Treatment should not be withheld for quality-of-life reasons. If mental retardation is being looked upon by some people as a reason in and of itself for non-treatment of a child at the option of its parents, then the physician is not acting in the best interest of the child as his patient. In the case of duodenal or esophageal atresia, if the condition is not repaired, one cannot feed the child normally. Nothing can be taken by mouth although intravenous feeding by gavage could maintain life optimally. The other option is not to feed. This has been universally condemned by ethics commentators. Generally the failure to treat leads to the choice not to feed, and the failure to feed leads to the hastening of death. According to Hans Jonas:

Now, as to the outright hastening of death by a lethal drug, the doctor cannot fairly be asked to make any of his ministrations for this purpose, nor the hospital staff to connive by looking the other way if someone else provides the patient with the means. The law forbids it, but moreso (the law being changeable), it is prohibited by the innermost meaning of the medical vocation, which should never cast a physician in the role of a dispenser of death, even at the subject's request.<sup>215</sup>

These issues have been complicated by the United States Supreme Court's legalization of abortion which casts the physician in the role of the dispenser of death. In the minds of many judges abortion is legally normative, just as any other "medical procedure" required by the applicable standard of care.<sup>216</sup> Thus, a failure on the part of the physician to include abortion or abortion referral as an alternative to birth with handicaps could render him liable in Tort to the defective child or to its parents because of recent developments in United States law.

### Infanticide

Baby Doe is the anonymous designation for those infants whose court cases earn public attention and news coverage. Their plight is the plight of thousands of other infants who do not elicit public recognition. Baby Doe is like the unknown soldiers of wars past whom we annually honor in remembrance of the sacrifices of the other thousands who cannot be identified. And the Baby Does, like the unknown soldiers, have had mothers and fathers who have cared for them, worried about them, and contended against obstacles to their welfare in the way that they, as parents, have thought best. Both groups of parents have

mourned the loss of their loved ones. And just as there are those who hold that young men should not have to die in war, there are those who hold that many Baby Does need not die in hospitals.

On April 9, 1982, a baby boy with Down's Syndrome was born in Bloomington, Indiana. American society would not have accepted that condition alone as sufficient cause for justifying the neglect which led to his death. But it was sufficient cause to move the baby's parents to find in his blocked esophagus (an easily repairable condition) justification for allowing their baby to starve to death. The pediatricians recommended unblocking the esophagus. But the parents, after consulting with their obstetrician, refused the corrective surgery for their infant. Their decision was based on the premise that their child had no chance of having "meaningful life."

Representatives of the hospital, not wanting to be a party to the parental decision, notified the state authorities. The state appointed lawyers to defend the child. The lawyers had to move fast if they were to save this infant life, but their petition was refused by two state courts, one being the Indiana Supreme Court. One judge declared that parents "have the right to choose a medically recommended course of treatment for their child in the present circumstances."<sup>217</sup> The pediatricians tried

to convince the parents to permit the operation. The baby was starving. He had been transferred to a private room because the nurse could no longer stand to hear his cries.

The child's lawyers went to the United States Supreme Court to argue the case. The doctors made one final attempt to save the infant. Carrying intravenous equipment and other apparatus for giving the child nourishment, they rushed to the bed of the dying child. They later submitted this report of their attempt to save him:

Baby Doe's shrunken, thin little body with dry, cyanotic skin, extremely dehydrated, breathing shallowly and irregularly, lay passively on fresh hospital linens. Blood was running from a mouth too dry to close. Death by starvation was near. Too late for fluids. Too late for surgery. Too late for justice.<sup>218</sup>

At Yale-New Haven Hospital reporters of the Hartford Courant found cases where parents had given their newborn children lethal overdoses of morphine or phenobarbital. The reporters also found that one couple, whose child had been treated against their will, had given their baby increased doses of an anti-convulsant sedative. After six days the baby had died. The doctor in the case sided with the parents, saying that the child was "socially dead and would never come alive." The parents declared: "We did it out of love."

Dr. Hugh Jolly of London's Charing Cross Hospital places babies who "might not enjoy a good quality of life...on a 'water only' diet, with sedatives if necessary." He refers to this as "conservative treatment."

In 1983, a nurse reported the following description of the termination of babies with Down's Syndrome:

The doctor would see the baby's head coming out through the birth canal, realize it had Down's Syndrome, and signal us to let it die. The mother's legs would be up so she couldn't see what was going on. We would get a little wave of the doctor's hand - a signal to us not to use suction on the baby. (Then) they'd say to the mother, "We're just going to give you something to relax you," and the next minute she'd be unconscious. When she came around, they'd say the baby had died on delivery.

The case of baby Jane Doe took place at Stonybrook Hospital in New York. She was born with spina bifida. She needed treatment early in life in order to prevent hydrocephalus, an accumulation of fluids in the brain which is often secondary to spina bifida. Her back, presenting with a bifid spine, also needed to be closed in order to prevent infection. At first her parents agreed to treatment. Later, after consulting with another physician, they withdrew their permission and asked for a more "conservative" treatment with antibiotics. They were told that without surgery their baby would die within two years.

A suit was filed claiming that the child was the victim of discrimination on the grounds that she had been denied necessary medical care because of her handicapping condition. The news media sympathized with the parents and reported that the parents had had to make an "agonizing decision" because the child could not be expected to enjoy "meaningful social interaction" and that if she were given treatment she would live only twenty years at most, and those years in pain and suffering. The public seemed to side with her parents.

The federal government sought for evidence of discrimination. Parents of other children with spina bifida, who knew what the potential of such babies is, pleaded with Baby Jane's parents to permit the necessary surgery. There were even offers to adopt the infant. The pessimistic assessment of the baby's potentiality reported in the news media was later contradicted. Medical authorities experienced in the management of infants with spina bifida came forward with assurances that, given the necessary medical treatment, Baby Jane's chances for normal intelligence and independent ambulation with braces were very good. There was nothing extraordinary about the recommended treatment. Only those surgical and medical procedures normally anticipated in the case of a child with spina bifida were proposed by those attempting to defend

the rights of baby Jane Doe. One attorney examining the case stated:

Not only have they said that the child is being medically neglected as no otherwise nondisabled child would be neglected, they admit she is being treated differently than children with problems exactly like hers are normally treated--all because doctors and the courts deem that...the parents have a private right<sup>220</sup> to preside over the death of an unwanted child.

At the root of the issue of infanticide in the practice of medicine is the response of physicians to pressures from the public and the trend toward assessing "quality of life." Prejudice is generally based upon the imposition of one's own self-image on others. That which is in our midst and unlike ourselves is suspect and possibly threatening. Professional people perceive their fellow creatures through the lenses of their professions. Some physicians may relate to people as biological entities, and their scientific practice may not relate well to the concept of the human soul and the sanctity of life. Physicians may be forced to recognize legal personhood as defined by the courts while at the same time finding it difficult to deal with the personhood of an infant so defective that they cannot personally relate to the child as a fellow human being. Some physicians find a kind of psychological effrontery in the proposition that the

defective are related and like themselves. It is as though they irrationally fear accidentally becoming themselves defective or capable of generating a defective child and thereby being themselves defective by implication.

In 1983, Dr. Peter Singer wrote in Pediatrics:

If we compare a severely defective human infant with a dog or a pig...we will often find the nonhuman to have superior capacities...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. But species membership alone is not relevant...if we can put aside the obsolete and erroneous notion of the sanctity of all human life, we may start to look at human life as it really is: at the quality of life that each human being has or can attain.<sup>221</sup>

When a society decides that the lives of its defective members are worthless, many physicians are willing to relinquish their traditional life-saving role and justify their participation in a technocratic final solution derived from that decision. Drs. Raymond Duff and A.G.M. Campbell were the first in the United States to describe large-scale withholding of treatment from defective newborns in response to social interests.<sup>212</sup> In 1973, they reported that forty-three children, some with Down's Syndrome and others with spina bifida, had been neglected until dead at Yale-New haven Hospital. They offered the following explanation as justification for their decision to withhold treatment:

We believe the burdens of decision-making must be borne by families and their professional advisors because they are most familiar with the respective situations. Since families primarily must live with and are most affected by the decisions, it therefore appears that society and health professionals should provide only general guidelines for decision-making.<sup>212</sup>

One fallacy in this explanation is that it underestimates the influence physicians have on their patients and on the families of their patients. The average patient looks to the advice and "guidelines" of the physician in order to determine a course of action. Esteem for the physician's opinion is even more pronounced in Europe than it is in the United States. Physicians who aggressively recommend the treatment of birth defects assume the traditional responsibility of advice and guidance. They recognize that parents without knowledge or experience cannot be expected to bear alone the burden of a life-or-death decision. Dr. David McLone of Chicago's Children's Memorial Hospital explains that, although parents must be fully informed and brought into the decision-making process, it is the physician's duty to recommend what is in the best interest of the patient, based on sound medical judgment and experience. Although the family's economic status and social needs are important and may necessitate the acceptance of social services and

the use of community resources, these needs should not determine the value of a human life.<sup>223</sup>

The findings from a survey conducted in 1977 by Drs. Shaw, Randolph, and Manard illustrate the extent to which physicians have moved from a sanctity-of-life perspective to a quality-of-life value system.<sup>224</sup> Nearly seventy-seven percent of pediatric surgeons and sixty percent of pediatricians who responded declared that they support the parents' decision to refuse surgery to correct the intestinal obstruction of their infant born with Down's Syndrome. Nearly twenty-four percent of the physicians surveyed responded that they would encourage parents to refuse corrective surgery for their infants born with Down's Syndrome and having intestinal obstructions. Fewer than four percent of these physicians answered that they would attempt to obtain a court order for treatment of the infants against their parents' wishes. Sixty-four percent stated that they would accelerate the dying process by withholding nourishment and care.<sup>225</sup>

One author addressed the issue of the parental right to decide whether or not an infant with Down's Syndrome should be treated:

Parents traditionally have had authority over their children. Our courts have recognized these parental rights many times. Parents usually love their children and we assume that they will act in their children's best interests. Parents and families are also the people who bear the burdens of raising a handicapped child. They are the ones who must find

the financial and emotional resources to deal with this new family member. In addition, each of these situations is extremely complex. There are many facets to be considered and only the family is able to analyze the many pieces of this 'tragic situation.' When we put all these factors together, doesn't it make sense that parents should have the right to decide their child's fate? After all, parents can decide the fate of their child before birth, why not give them the same power after birth? If the parents want their baby, then every effort should be made to save the child. But if they don't want this child, then we should 'let nature takes it's course.' Why not just carry the doctrine of 'every child a wanted child' one step further? If a born child is unwanted, let it die (or kill it) <sup>226</sup>.

Melinda Delahoyde detects the danger in a doctrine that implies the absolute right of another to impose a death sentence on new life merely because it is unwanted. She is the mother of a child with Down's Syndrome, and in her book Fighting for Life, she writes:

We live in a society where we destroy unborn children because they are the wrong sex. What makes us think that we can tolerate 1.6 million abortions a year and still have a society where parents unconditionally accept their newborn children? How can we think that the mentality of easy abortion and cheap life will <sup>not</sup> infect our attitudes toward our newborn children? <sup>226</sup>

John Robertson, a law professor specializing in issues addressing children's rights, has listed the crimes that parents and doctors may commit when neglecting a handicapped child:

Every state imposes a duty upon parents to care for their children. When they fail to uphold this duty and their child dies, they can be prosecuted for manslaughter or murder. Care for a child cannot be withheld because of cost or parents' wishes.

Parents can also be prosecuted under child abuse laws for failure to care for their children, and for cruelty or neglect in failing to provide necessary medical care.

The doctor and hospital have a contractual obligation to provide treatment when they admit a patient or enter a case. This obligation remains in force even if parents do not give their consent to treatment for their child.

If parents refuse treatment, the doctor and hospital may ask the parents to remove the child from their care or they may ask a court to appoint a guardian who can consent to treatment on behalf of the child.

The doctor who counsels the parents to withhold treatment or who merely agrees with their decision can be guilty of failure to report child abuse in at least twenty states.

Since reporting the abuse of the child might have saved the child's life, the doctor who fails to report nontreatment could be guilty of manslaughter.

The doctor may be guilty of murder by omission because he did not uphold his duty to care for the child and, as a result of his nontreatment, the child died.

The doctor has a legal duty to care for the child and to report when the child under his care is being neglected. The doctor could withdraw his treatment or decide not to treat the child only if he has notified public authorities who would act to protect the child.

The doctor also has a legal duty to protect the child. By his providing information to the parents the child may be imperiled.

The doctor may also be subject to prosecution for murder because he is an accessory to the death of

the child. A doctor who counseled or encouraged parents not to treat their child would be someone who "counsels, encourages, or aids...another to commit a felony."<sup>211</sup>

Nurses who withhold treatment are also at risk. In some cases, a nurse is responsible to act in opposition to doctor's orders if protection of the patient requires it. In another case the courts have found that nurses have a duty to at least report such a situation to their supervisor.

Doctors could also raise a petition to a court to treat a child over the parents' objections. In such a case the court is likely to grant treatment as it did in the 1974 Houle case in Maine.<sup>227</sup> In this case, parents refused consent for surgery to correct a badly formed esophagus in their newborn child. The baby had an unknown measure of brain damage and no left eye or ear. In this case the court showed itself to be a strong protector of newborn life:

At the moment of birth there does exist a human being entitled to the fullest protection of the law. The most basic right enjoyed by every human being is the right to life it- self. The issue before this court is not quality of life to be preserved. Being satisfied that corrective surgery is medically necessary and medically feasible, the court finds that the defendants have no right to withhold such treatment.<sup>227</sup>

It would seem that our society is attempting to accommodate two irreconcilable opinions. One is exemplified

by those who advocate extending the doctrine of "every child a wanted child" to "Let the unwanted child die, or kill it." The other is exemplified by the judge's opinion in the 1974 Houle case in Maine that the issue before the court was not quality of life but life itself. Both of these positions are responses to what are called parental rights. Resorting to the courts to resolve the question of wrongful death of the newborn has surprisingly led to appealing to the courts for what is now called "wrongful birth." And physicians are ironically the primary targets of both charges. United States courts have become battlegrounds for the forces of common law and precedent on the one side and the pressures of a society irreversibly influenced by technological developments on the other.

### Wrongful Life

Anyone who believes that either "wrongful life" or "wrongful birth" is an oxymoron or a perversion of the legal theory of wrongful death is compelled to face the reality that these concepts have not only entered the consciousness of the public domain but have also entered the domain of court deliberations.

The intercession of the court is attributable to public demand. The physician's greatly increased powers to

sustain life because of new medical technology subject him to the charge of "wrongful life." The technological means of detecting defects in utero subject the physician to the charge of "wrongful birth" if he fails to avail himself of those means.

It should be emphasized that charges based on both the concept of wrongful birth and the concept of wrongful life have not been dismissed out of hand. The cases have been heard and opinions have been handed down.

The handicapped child is himself the plaintiff in a wrongful life case. The defendant may be a physician, a hospital, a laboratory, or even his own parents. The defendant is charged with allowing the plaintiff to be born. The action is based upon his claim that life with the handicap is worse than no life at all and that it would have been better had he never been born.

In a 1967 wrongful life case, a New Jersey court denied damages to a child born with Down's Syndrome. The judge's opinion was that:

One of the most deeply held beliefs in our society is that life--whether experienced with or without a major handicap--is more precious than non-life...To rule otherwise would require us to disavow the basic assumption upon which society is based...(and) this we cannot do.<sup>228</sup>

In contrast to the New Jersey court's opinion of 1967 is the 1980 opinion of the California Court of Appeals. The court recognized the claim of wrongful life brought by a girl born with Tay-Sachs disease. Because the Supreme Court's Roe v. Wade decision legalized abortion, and because prenatal detection made it possible for a physician to determine whether or not a mother was carrying a handicapped child, the court held that the child could claim that the parents should have aborted the child instead of having allowed it to be born handicapped. The judge opined:

If a case arose where, despite due care by the medical profession in transmitting the necessary warnings, the parents made a conscious choice to proceed with a pregnancy, with full knowledge that a seriously impaired infant would be born...we see no sound public policy that should protect those parents from being answerable for the pain, suffering, and misery that they have wrought upon their offspring.<sup>229</sup>

Even more acceptable to courts have been wrongful birth cases. In such cases parents sue their doctor for not giving them information about birth defects detectable in utero.

Societal Interventions and Working Towards Self-Respect

Our society's definition of the rights of the handicapped has developed not only through judicial processes, but also through changing social attitudes and governmental policy. The right to enjoy freedom, self-determination, and independence granted to the individual and to the family has been extended to the individual who is handicapped. Advocacy for the benefit of the handicapped has historically been the prerogative of charitable organizations which determined and controlled the kind of support they should receive. In sum, the non-handicapped have traditionally controlled the destiny of the handicapped. This tradition is based upon the conviction that the fortunate have an obligation to see to the welfare of the less fortunate and that the giver is more benefitted than the receiver. Despite the undeniable good bestowed upon the receiver, the pattern of dependency that was established was often perceived as demeaning and confining for the intended beneficiaries.

Although great change has come about in the United States since the days of the "Benevolent Society" and the "Women's Welfare League for the Salvation of the Feebleminded," many characteristics of their motives and

methods remain and are, from time to time, recognizable in the motives and methods of organizations currently devoted to the same cause. One such characteristic is best described as eugenic expectation, the belief that society should strive for perfection and that any means toward this end may be justified. Abhorrence or fear of those members of society who do not measure up to expectations of "normality" may be at the root of the rejection of those who do not act, speak, look, or smell quite the same as the rest of us. The case of Carrie and Vivien Buck is dramatically illustrative of an attitude which is far from dead.

Carrie Buck was only one among many victims of a discredited social theory--a theory which nevertheless was to be given practical application after it was propounded by an influential political movement of the 1890's. The practice of compulsory sterilization of so-called undesirable elements was accompanied by the imposition of national quotas set to discriminate against immigrants deemed mentally unfit because of the results of the I.Q. tests. The publicly proclaimed goal of excluding the "shiftless" and the "stupid" and of preventing the reproduction of any more like them was zealously pursued. Improved medical techniques for performing vasectomies and tubal ligations made a program of compulsory sterilization

easy to carry out. Some states passed laws mandating sterilization of those judged insane or mentally deficient, sterilization of those convicted of rape, and sterilization of those convicted of other crimes. Some states had lists of the defects deemed appropriate cause for sterilization that included alcoholism, drug addiction, blindness, and deafness. Laws mandating sterilization were most vigorously obeyed in California and Virginia. Approximately 20,000 forcible sterilizations had been performed in the United States by 1935, nearly half of them in California. A private organization with an aura of officialdom called the Eugenics Record Office lobbied and campaigned for eugenic sterilization "to prevent the procreation of persons socially inadequate from defective inheritance, by authorizing and providing for eugenical sterilization of certain potential parents carrying degenerate hereditary qualities." A model bill composed by Harry Laughlin, superintendent of the organization, called for sterilization of the "blind, including those with seriously impaired vision; deaf, including those with seriously impaired hearing; and dependent, including orphans, ne'er-dowells, the homeless, tramps, and paupers."

Harry Laughlin's call for prevention of the procreation of the socially inadequate cannot be dismissed as a lunatic aberration of the times when some of his

reasoning is reflected in a United States Supreme Court decision.

In 1927, the United States Supreme Court voted eight to one to uphold the Virginia sterilization bill in the case of Buck v. Bell.<sup>230</sup> The majority opinion was written by the then eighty-six-year-old Oliver Wendell Holmes:

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the state for these lesser sacrifices...It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough.<sup>230</sup>

Carrie Buck was eighteen in 1924 when Virginia passed its compulsory sterilization law. She was an involuntary inmate at the State Colony for Epileptics and the Feebleminded and the first person selected for sterilization under the new law. The basis for her selection was that, as Judge Holmes put it, she was "a feeble-minded White woman who was committed to the State Colony...She is the daughter of a feeble-minded mother in the same institution, and the mother of an illegitimate feeble-minded child." It was a matter of the inheritability of mental deficiency and the danger that this pollution of

the gene pool would pose to society if left to reproduce itself.

In 1980, Dr. K. Ray Nelson examined the records of the institution where he served as director and where Carrie Buck had been sterilized. He discovered that over 4,000 sterilizations had been done there and that the last had been in 1972. Carrie Buck was still alive and well at seventy-four years of age. Dr. Nelson found her to be as well as her sister who had also been sterilized under the same law. Doris had been told that her operation was for appendicitis. In her old age she learned why she had never been able to have a baby, something she had always wanted.

It is now clear to anyone who examines the record of Carrie Buck's institutionalization that she is not now nor ever was retarded. Law professor Paul Lombardo, a leading scholar of the Buck v. Bell case wrote:

As for Carrie, when I met her she was reading newspapers daily and joining a more literate friend to assist at regular bouts with the crossword puzzle. She was not a sophisticated woman, and lacked social graces, but mental health professionals who examined her in later life confirmed my impressions that she was neither mentally ill nor retarded. <sup>230</sup>

According to those who have examined the case retrospectively, Carrie Buck had originally been confined in the institution for the feebleminded because she was pregnant

with an illegitimate child. Carrie was herself one of several children born to her mother, Emma, out of wedlock. J.T. and Alice Dobbs were her foster parents. She had been raped by a relative of her foster parents and was blamed for her pregnancy. It is speculated that she was committed to the State Colony in order that her shame might be hidden and the identity of the rapist kept secret. Her mental capacities were not questioned at the time of her commitment. As for the motives of those who pressed for Carrie Buck's sterilization, they are revealed in the claim that the sterilization was for the sake of sexual morality and the prevention of social deviance. Harry Laughlin of the Eugenics Record Office wrote in his "family history" of the Bucks: "These people belong to the shiftless, ignorant and worthless class of anti-social Whites of the South."

An examination of the school report cards of Vivien Buck, Carrie Buck's illegitimate child who, at the age of eight, had died of enteric colitis, reveals that she had received good grades in her few years at school. It would seem, then, that every part of the United States Supreme Court's opinion has clearly been disproved. It is not difficult to see now that Society and the State reached unfairly and without just cause into the heart and soul of Carrie Buck's womanhood and destroyed her capacity to be a mother both physically and emotionally. It should be

remembered that the action against her was taken in the name of "enlightened science."

Over the entrances to the museums which are all that remains of the Nazi concentration camps are the German words for Never Again, but there is little in human history that cannot repeat itself. Harry Laughlin's model eugenics bill, adopted by so many of our states, served as a basis for the infamous and stringently enforced Erbgesundheitsrecht (Right to Healthy Inheritance) and led, by the eve of World War II, to the sterilization of some 375,000 people, most of them for "congenital feeble-mindedness", but including also nearly 4,000 for blindness and deafness. In 1982, the National Institutes of Health held a conference at the Hilton Hotel in Washington, D.C. to discuss the possibility of prenatal detection and abortion procedures to prevent the birth of children with neural tube defects (spina bifida). Obstetricians stood and gave testimony of abortions they had performed just days before term if the slightest defect was detected. Laboratory executives declared loudly and unashamedly that it is imperative to stop the "pollution of the gene pool." But it was the testimony of the very capable and happy-to-be-alive "handicapped" and their parents, the "polluters," which dissuaded the government from proceeding with the enactment of mandatory testing. Today this issue has become

a moot point because most obstetricians order prenatal testing for birth defects in order to protect themselves from legal liabilities for the birth of a defective infant.

Do children have a right to kill themselves?

Although all states have sanctions against attempting suicide and courts consistently find a countervailing state interest in the prevention of suicide by refusal to accept medical treatment, only two states hold completed suicide a crime, those states being Alabama and South Carolina. Dr. Hoberman describes a "movement in society at large and in legislatures and the judiciary to soften this prohibition, and to possibly identify or establish a right to kill oneself."<sup>231</sup> The effect that such a movement could have on an already increasing incidence of adolescent suicide is the concern addressed here.

Two questions evolve from a concern about sanctioned suicide: What would the impact of sanctioned or assisted suicide be upon adolescents and should adolescents have the right to self-termination? A first step in dealing with these issues is an understanding of current trends in adolescent suicide. Contrary to popular beliefs, the youthful suicide victim is not the "brilliant but neurotic" young student, but rather an individual with a psychiatric disorder. In a review of over eight hundred suicide cases in Minnesota, Hoberman and Garfinkel found that sixty-six

percent of them showed evidence of psychiatric disorder. Substance abuse, depression, and affective disorders led the list of related factors.<sup>231</sup> There is often a precipitating stress or occurrence which the child is unable to cope with successfully. In the study by Hoberman and Garfinkel precipitators included an argument for twenty-four percent, the breakup of a relationship for seventeen percent, trouble with the police for eight percent, trouble at work for seven percent, and trouble at school for six percent. Forty percent had used mind-altering substances within twelve hours of killing themselves.<sup>232</sup> Youth who complete suicide are also more likely to have access in their homes to lethal devices such as firearms or poisons.<sup>233</sup>

Despite the narrow range of possibilities that suicidal individuals see in coping with the pain and frustration they suffer and the desire to terminate consciousness in order to avoid that pain, they continue to express ambivalence. They often reach out to communicate their suicidal feelings to others. For every completed suicide there are hundreds of attempts. Although it may be a mistake to compare too closely those who attempt suicide with those who commit suicide, because they often seem to express different motives, the ambivalent nature of the act is apparent in both cases. Youthful suicide appears to be

more often spontaneous than contemplated. In the Hoberman and Garfinkel study only one third of the victims made any preparations or left any notes. Most committed suicide in their own homes, and in half of the cases there was someone at home or someone who was likely to get in touch with them. Twenty-eight percent of them made an active effort to avoid detection during the act.

According to Hoberman, securing the right to kill oneself would have little effect on those factors directly related to youth suicide:

The typical youth suicide is not an emotionally balanced youth who, over time, rationally deliberates over the meaning of life versus death and then chooses death, but rather an anguished young person who desperately wants to cut off his or her intense pain. Given this state of affairs, a right to suicide and the philosophical and legal arguments in its support will not matter to this disturbed young person. Certainly most, if not all young people, who commit suicide neither know nor care whether they have a right to do so; suicide is too much a desperate act of the moment.<sup>233</sup>

A sanctioned right to suicide might, however, have a more significant impact upon the indirect factors influencing youth suicide. The contagion effect resultant from the publicizing of a youth suicide is well known. Hoberman projects that the rate of youth suicide would be substantially influenced and would correlate directly to the "degree that a right to suicide is established and

receives attention as society and the judiciary wrestle with the definition and limits of that right."

Questions about the evaluation of "quality of life" will also come into play. A legally sanctioned right to suicide suggests that life is not intrinsically valuable and that there may be circumstances in which the value or meaning of life may come into question. Young people may become desensitized to death through consideration of circumstances which the public may define as adequately painful, burdensome or limiting such that death may be desirable. If suicide is portrayed as an honorable escape from failure, as it is in some cultures, then the rate of suicide among youth may rise. That rate is higher even now in Japan where youth may be found to commit suicide more frequently upon the failure of school entrance examinations. If youth come to understand that society justifies suicide in cases where the "quality of life" is limited because of pain or "lifestyle limitations" they may have difficulty distinguishing between their own emotional suffering and the physical suffering of the terminally ill patient.

Should adolescents be granted the right to assist in the suicide of another? Hoberman suggests two arguments against this proposition: first that youth are "not equipped mentally, emotionally, or experientially to make a

decision of that magnitude," and second, there is the legal question. There is clear acceptance that certain behaviors which are permissible for adults may not be permissible for youth: the age at which driving or drinking alcohol is permitted, or when curfews may be imposed, for example. There are standards in society which are particular to the age, experience and abilities of those they affect: "The power of the state to control the conduct of children reaches beyond the scope of its authority over adults," was declared by the United States Supreme Court in Prince v. Commonwealth of Massachusetts.<sup>234</sup> And in Ginsberg v. New York: "A child...is not possessed of that full capacity for individual choice" necessary for the exercise of rights.<sup>235</sup> It is the responsibility of the state to intervene on behalf of the child that he may develop to adulthood and become a responsible citizen."

Hoberman points out some legal arguments that seem to potentially contradict the court's conclusions. Under the right to privacy, "personal decisions" by minors have been protected. Minors are allowed access to abortion without parental consent. Many people would argue that abortion is indeed the termination of life. Minors are not prohibited from procreation. A right to self-termination would arguably be included in the doctrine of privacy and the protection of personal decisions for adolescents. It

appears that the debate will continue. As long as adults are ambivalent about an issue, they will find adolescents following their example.

## CHAPTER 4

A KANTIAN PERSPECTIVE: AN EXAMINATION OF THE PRINCIPLES GOVERNING THE RIGHTS AND OBLIGATIONS IN HUMAN RELATIONSHIPS PRESENTED BY IMMANUEL KANT IN HIS ESSAY, FUNDAMENTAL PRINCIPLES OF THE METAPHYSIC OF MORALS.

Kant develops a theoretical approach to the principles of morality in the public and private relationships that people have with each other in his Fundamental Principle of the Metaphysic of Morals.<sup>236</sup> Two of his other works, The Fundamental Princiles of Jurisprudence and The Science of Right,<sup>237</sup> also address the problem of determining the boundaries of right and obligation which human beings should ideally recognize and honor in all of their relationships. Concepts of human relations lie at the heart of almost all of Kant's work, even though his discussion may take the form of a theoretical conceptualization of existence, of the nature of things, or of the laws of logic. It is these concepts as they impinge upon man as a social being that were of paramount concern to Kant, throughout his life. Even when he was near death, in 1804, he thanked the medical

attendant ministering to his needs and declared, "I have not yet lost my feeling for humanity."<sup>238</sup>

Although Kant's earlier work may be marked by a more dogmatic approach to human rights and obligations, and may reflect the influence of the writings of Leibniz and Wolff,<sup>239</sup> his mature work shows the influence of David Hume. There is no tinge of dogmatism in the new philosophy he developed. This philosophy is based upon a critical examination of the fundamental principles which govern existence, action, time, substance, and experience.

It is not the purpose of this work to criticize and interpret the philosophy Kant developed, but an eclectic gleaning of his reasoned conclusions as to the principles governing existence and experience, and his insight into the intricacies of human right and obligation, will serve as the "Kantian perspective" through which an understanding of family-society conflict is attained. Understanding is the first step toward identifying those principles which might provide a basis for the resolution of the conflicts which arise between families and the state when the rearing of handicapped children is undertaken.

If the Kantian approach is to be the vehicle for achieving understanding and resolution, then a definition of what such an approach constitutes must be established. Kant's method of reasoning is not unique, and the

principles he developed are not exclusively his own. It is the pattern of critically weighing and then affirming, of inquiring into the condition of knowledge, and then expressing assumptions, that is characteristically Kantian. His is a theory of ideas critically discriminating between things sensed and things apprehended by means of pure reason. In this respect his theory is unlike the theories of either Leibniz or Locke. Kant held that the substance of our ideas is determined by means of the senses and that the form of our ideas is determined by our reason. The complexities of sensation are refined into ideas by means of reason. What is new and revolutionary in Kant's thought is the philosophical element of what was later recognized as the Romantic Revolution:

It is with Kant that something really and positively new makes its appearance in post-Renaissance moral philosophy. In the process of summing up and concentrating in himself, the complex heritage and the long effort of three centuries of thoughts, he performed a revolutionary task in the realm of ethical philosophy, as in that of speculative philosophy. Not that he wished to destroy or overthrow anything in the realm of morals--on the contrary, his effort was to restore. But in order to construct his imposing edifice, he was, in fact, compelled to transform completely the whole architecture of ethics. <sup>239</sup>

Kant's approach to philosophy, although prompted by the works of Hume, was indeed revolutionary. Prior to Kant, there had been agreement among philosophers that their

knowledge of the world obtained its validity through objects, although there were radically divergent concepts as to what objects really are. For Plato, forms constituted the immaterial realities, or imitations of the absolute, which made up objects. For Berkeley, material objects existed only as ideas in the mind. For Aristotle, whose influence pervaded the expressions of almost all later philosophers, objects were themselves fundamental realities. There was not generally any dispute as to our ability to know objects, although some attempted to explain what seemed to be obvious that we do indeed know that objects really do exist.

Kant's Critique of Pure Reason<sup>240</sup> was revolutionary because it did not assume as fact that we know that we have knowledge of objects in themselves. Such knowledge Kant declared to be impossible. Rather than an objective reality known by our perception in the mind, the universe, or nature is actually a formal system made manifest through our senses. True knowledge for Kant was limited by human experience itself. To philosophize about matters beyond experience, such as the nature of God, the freedom of the will, or the immortality of the soul, would not be productive. This approach overturned the cherished dogmas heretofore espoused by philosophers, and led to the idealism which reflects the romanticism of the 19th and

20th centuries. This, in turn, led to phenomenology, and through phenomenology to existentialism. Kant's concerns were not limited to objects or facts of substance but included areas of moral philosophy. Moral philosophers prior to Kant had agreed that there were standards for judgment which could be found in some objective element. Human nature was the moral guide to action for Aristotle. Man's rational perception of natural law was reflected in the law of God for the scholastics of the Middle Ages. Although there was not consensus as to what exactly the appropriate value object should be, philosophers agreed that there was some guide by which man could choose as he sought for virtue and goodness.<sup>241</sup>

Kant, however, found it impossible to know objects except through experience. Even human nature as it exists in itself could not otherwise be known, except in experience. In order to avoid a purely subjective moral standard, one has to appeal to reason as a source of moral goodness rather than to a preconceived idea. A consistency of action, then, becomes an indication of morality rather than a value object.

Translating this concept into language understandable to a public which expressed itself in the language of objects was a formidable task. Apparently Kant assumed that readers of his Foundation for Metaphysics of Morals, which

was his first major work in moral philosophy, would have read his Critique of Pure Reason, and thereby would recognize his peculiar usage of certain expressions. The basic terminology must be mastered before one can begin to understand the philosophy itself. Kant's primary objective in the work, Foundation for a Metaphysics of Morals is, as he himself states "to discover, and justify, the supreme principle of morality." Thus he attempts to discover an ultimate foundation for morality upon which the structure of moral law can rest, and which is based upon duty. To understand Kant's moral theory, there must be a clear understanding of what Kant means by speculative and practical reason. Both, as Aristotle points out, are activities of man's rational soul, but they concern different objects of thought. In speculative wisdom (Sophia), knowledge of eternal and necessary truths such as mathematics is manifest, whereas in practical wisdom (Phronesis), knowledge of right principles for living the good life is manifest. Both are conceptual, and may not necessarily relate to actual experience. Practical knowledge comes through actual hands-on skill development. Kant distinguishes between these two by saying, "It may be sufficient in this place to define theoretical knowledge, or cognition as knowledge of that which is, and practical knowledge as knowledge of that which ought to be."<sup>1</sup> In

general. Kant uses the term speculative reason to denote the rational faculty whereby we know things, or facts, and the term practical reason to denote that faculty through which we can determine what we ought to do. Practical reason depends on actions that we may choose to do or not choose to do, but ought to do, whereas speculative reason has to do with what is, and was, and will be, indeed, a matter of fact. Knowing things, according to Kant, can be achieved by two means. We have two ways of knowing facts and two ways of knowing what to do. We have an everyday way, that is, by experience through our senses. This is not pure reason, according to Kant. By pure reason he refers to that reasoning which is free from everything derived from experience. Thus, pure reason revolves around the activity of reason itself rather than an experience. Some may argue that reasoning itself is an experiential process. It is the framework of our knowledge, or the construction of knowledge itself, that we cannot know through experience, that is the pure reason. How meaningful to us our experiences are is determined by a standard other than the experience itself. This condition for our empirical knowledge is not known by the experience itself, since in order to place the experiences we have into some context, we must have that framework within us, and to understand this framework we must do so independently of the ex-

perience or the things that we experience--that is, by an activity of reason without necessary experience, in other words, by pure reason. Kant limits his examination of pure reason to the fundamental activities of reason as it forms in separate experiences into meaningful wholes. Kant distinguishes between speculative and practical reason. The activity of reason takes sensations from the senses, uniting them to form experiences of the universe. In this case, Kant refers to this activity as pure speculative reason, and his critique of pure reason outlines this principle. However, when the activity of reason, as it constructs rules of activity, is investigated, then Kant is dealing with pure practical reason, and this is his primary task in the foundation of morals in his Critique of Practical Reason. When Kant refers to a critique of pure practical reason, he is referring to his investigation into the fundamental and purely rational prerequisites of all moral knowledge. In the Foundation for the Metaphysic of Morals, Kant seeks to establish the ultimate framework or condition which will justify all other moral laws by establishing their objective validity. Kant sets out by reasoning to discover a system of laws of choice and action in order to prove them to be a valid foundation for moral principles. His goal is to find an ultimate standard for moral judgments. Otherwise, morality would appear to be a

relative matter, merely a codification of preferences or customs requiring no particular insight as to why choices should be one way or another.

Kant speaks of the concept of a priori as that which is derived from reason and that which is a posteriori as that which is derived from our experiences. If the necessity of something is derived from the meaning of the term itself, then one can see by reason alone that something may be true. That would mean a self-contradiction. Because of the necessary nature of moral rules they are a priori from Kant's point of view, and propositions of practical reason. Thus, they've derived their authority from reason rather than experience.

### An Examination of the Foundation of the Metaphysic of Morals

Kant finds the moral significance of every action in three elements--the source of the action, the result intended, and the motive for the action. The first element, the will, is the primary or ultimate objective of morality.

Nothing in the universe--in fact, nothing whatsoever--can we possibly conceive as absolutely good except a good will.<sup>242</sup>

By good will. Kant means that which actively and consistently chooses to do the right thing, to perform the good deed; and does so from the right motive. Kant justifies the pronouncement of good will as the absolute good:

Intelligence, wit, judgment, and the other talents of the mind, however they may be named, or courage, resolution, perseverance, as qualities of temperament, are undoubtedly good and desirable in many respects; but these gifts of nature may also become extremely bad and mischievous if the will which is to make use of them, and which, therefore, constitutes what is called character, is not good. It is the same with the gifts of fortune. Power, riches, honour, even health, and the general well-being and contentment with one's condition which is called happiness, inspire pride, and often presumption, if there is not a good will to correct the influence of these on the mind, and with this also to rectify the whole principle of acting, and adapt it to its end. The sight of a being who is not adorned with a single feature of a pure and good will, enjoying unbroken prosperity, can never give pleasure to an impartial rational spectator. Thus a good will appears to constitute the indispensable condition of being worthy of happiness. <sup>243</sup>

These characteristics appear to describe qualities of an individual, but they may be as easily applied to groups, or society in general. For example, a society may demonstrate its people's high level of intelligence, but if they are selfish in the application of that intelligence it is not of benefit, or good will. If intelligent people demonstrate disdain for the retarded, then they are, in spite of their intelligence, without good will. If a so-

ciety is rich because of the blessings of the natural resources of its environment, it is not necessarily conducive to good will if those resources are not applied with kindness towards those who can benefit from them.

There are even some qualities which are of service to this good will itself, and may facilitate its action, yet which have no intrinsic unconditional value, but always presuppose a good will, and this qualifies the esteem that we justly have for them, and does not permit us to regard them as absolutely good. Moderation in the affections and passions, self-control and calm deliberation are not only good in many respects, but even seem to constitute part of the intrinsic worth of the person; but they are far from deserving to be called good without qualification, although they have been so unconditionally praised by the ancients. For without the principles of a good will, they may become extremely bad, and the coolness of a villain not only makes him far more dangerous, but also directly makes him more abominable in our eyes than he would have been without it.<sup>244</sup>

In order for an individual or a group to be morally good, a good will is not necessarily sufficient. There is a difference between a good agent and a good action, between the person or the group which acts or votes to act and the deed that is actually performed. The action is independent of the moral character of a person himself or of a group itself. Misappropriated funds can be used to care for the homeless as well as revenues honestly procured. An individual or a group can only receive moral credit, according to Kant, when the action is done for the right reason. Indeed, Kant maintains that the moral value of the

intent is of benefit, whether the individual or group succeeds with the action or not.

A good will is good not because of what it performs or effects, not by its aptness for the attainment of some proposed end, but simply by virtue of the volition, that is, it is good in itself, and considered by itself is to be esteemed much higher than all that can be brought about by it in favour of any inclination, nay, even of the sum total of all inclinations. Even if it should happen that, owing to special disfavour of fortune, or the niggardly provision of a step-motherly nature, this will should wholly lack power to accomplish its purpose, if with its greatest efforts it should yet achieve nothing, and there should remain only the good will (not, to be sure, a mere wish, but the summoning of all means in our power), then, like a jewel, it would still shine by its own light, as a thing which has its whole value in itself. Its usefulness or fruitfulness can neither add to nor take away anything from this value. It would be, as it were, only the setting to enable us to handle it the more conveniently in common commerce, or to attract to it the attention of those who are not yet connoisseurs, but not to recommend <sup>247</sup> it to true connoisseurs, or to determine its value.

Unless an individual has a good will or unless a group has a good will, neither can receive moral credit for its actions. If one does have a good will, one may receive such credit in spite of the outcome. Kant wishes to establish that reason is the appropriate foundation of moral action. To give grounds to morality and reason, he must take the route of good will which is established through reason, giving an a priori grounds to morality. The concept of duty, or the moral "ought," is the second element of

morality for Kant. To act solely from duty constitutes the moral motive of the good will. Any concept involving the a priori necessity cannot depend upon experience, but there must be some experience in each particular duty, otherwise we would not know what we ought to do. The moral necessity of action has its foundation in reason, not in experience, and the conceptual form of moral necessity is an a priori concept of practical reason. And so, we discover the good will through duty.

I omit here all actions which are already recognized as inconsistent with duty, although they may be useful for this or that purpose, for with these the questions whether they are done from duty cannot arise at all, since they even conflict with it. I also set aside those actions which really conform to duty, but to which men have no direct inclination, performing them because they are impelled thereto by some other inclination. For in this case we can readily distinguish whether the action which agrees with duty is done from duty, or from a selfish view. It is much harder to make this distinction when the action accords with duty, and the subject has been besides a direct inclination to it. For example, it is always a matter of duty that a dealer should not overcharge an inexperienced purchaser, and wherever there is much commerce the prudent tradesman does not overcharge, but keeps a fixed price for everyone, so that a child buys of him as well as any other. Men are thus honestly served; but this is not enough to make us believe that the tradesman has so acted from duty and from principles of honesty: his own advantage required it; it is out of the question in this case to suppose that he might besides have a direct inclination in favour of the buyers, so that, as it were, from love he should give no advantage to one over another. Accordingly the action was done neither from duty nor from direct inclination, but merely with a selfish view.<sup>246</sup>

There are three ways in which duty may be related to actions. Actions may conflict with duty and, therefore, would not involve a good will, or they may be in accord with duty, but nonetheless not executed for the right reason--that is, because of a moral motive. The motive may be some inner compulsion, such as love or a sense of honor. Or the motive may be a desire for particular gain. Actions may also be done from duty, that is, in recognition of the ought. This is what Kant refers to as from duty or aus Pflicht, or for duty's sake. All actions that are not motivated by pure moral interest are, according to Kant, inclinations or desires, that is, based upon self-interest. This would include benevolence, philanthropy, and parental love, and even selfish greed, the desire for sensual pleasure, and fear. Thus, there are only two reasons for performing an action, either because it is our duty or obligation, or because of some other reason, which Kant would refer to as an inclination, or a selfish motive.

On the other hand, it is a duty to maintain one's life; and, in addition, everyone has also a direct inclination to do so. But on this account the often anxious care which most men take for it has no intrinsic worth, and their maxim has no moral import. They preserve their life as duty requires, no doubt, but not because duty requires. On the other hand, if adversity and hopeless sorrow have completely taken away the relish for life; if the unfortunate one, strong in mind, indignant at this fate rather than desponding or dejected, wishes for death, and yet preserves his life without loving it--not from

inclination or fear, but from duty--then his maxim has a moral worth.<sup>247</sup>

Here Kant introduces the concept of a maxim, which he defines as a subjective principle of action. His personal rule or policy which people follow when they act is a kind of general policy and outlines a procedure for acting in a certain kind of situation. In Kant's example of a duty that an individual may feel to preserve his life, the contented man determines that as long as his life is pleasant, he will do what he can to preserve it. Another might say, "When my life becomes intolerable, I will commit suicide." These are subjectively the maxims of the individual and do not suggest principles that he would impose on others. But if there is a duty to hang on to life, even when that individual lacks the inclination to do so, he would have to have a maxim such as, "I must try to live as long as possible." Such a maxim would be grounded in a good will moral foundation. Thus, he would be acting for duty's sake and not merely from inclination. And the maxim would have a moral value.

To be beneficent when we can is a duty; and besides this, there are many minds so sympathetically constituted that, without any other motive of vanity or self-interest, they find a pleasure in spreading joy around them and can take delight in the satisfaction of others so far as it is their own work. But I maintain that in such a case an action of this kind, however proper, however amiable it may be, has nevertheless no true moral worth, but is on a level

with other inclinations, e.g. the inclination to honour, which, if it is happily directed to that which is in fact of public utility and accordant with duty, and consequently honourable, deserves praise and encouragement, but not esteem. For the maxim lacks the moral import, namely, that such actions be done from duty, not from inclination. Put the case that the mind of that philanthropist were clouded by sorrow of his own, extinguishing all sympathy with the lot of others, and that while he still has the power to benefit others in distress, he is not touched by their trouble because he is absorbed with his own; and now suppose that he tears himself out of this dead insensibility, and performs the action without any inclination to it, but simply from duty, then first has his action its genuine moral worth. Further still; if nature has put little sympathy in the heart of this or that man; if he, supposed to be an upright man, is by temperament cold and indifferent to the sufferings of others, perhaps because in respect of his own he is provided with the special gift of patience and fortitude, and supposes, or even requires, that others should have the same--and such a man would certainly not be the meanest product of nature--but if nature had not specially framed him for a product of nature--but if nature had not specially framed him for a philanthropist, would he not still find in himself a source from whence to give himself a far higher worth than that of a good-natured temperament could be? Unquestionably. It is just in this that the moral worth of the character is brought out which is incomparably the highest of all, namely, that <sup>248</sup> he is beneficent, not from inclination, but from duty.

Here Kant introduces actions which may be good without having moral value. They may be done from praiseworthy motives, but they do not have moral value. they are done from desire or some other human motive. Such actions may be praised and their perpetrators considered honorable, but, according to Kant, our esteem is owed only to that virtuous person who acts from the moral motive. If an individual has indeed a moral motive for his actions and yet may also have some other human motive, that second motive does not negate the morality of the action.

The primary purpose of reason which is, according to Kant, man's ultimate goal is to have a good will in that we might be worthy of happiness. Man must have some goal which he can obtain on his own and that goal for Kant is man's worthiness to be happy, the goal that every man can achieve regardless of the vicissitudes of life. The kind of worth that Kant is speaking of in the worthiness to be happy is moral worth, which is the goal to be attained through reason. The goal of every being endowed with a rational nature is moral worthiness. And the necessary and sufficient condition for attaining this worthiness is the good will.

Reason is imparted to us as a practical faculty, i.e. as one which is to have influence on the will, therefore, admitting that nature generally in the distribution of her capacities has adapted the means to the end, its true destination must be to produce a will, not merely good as a means to something else, but good in itself, for which reason was absolutely necessary. This will then, though not indeed the sole and complete good, must be the supreme good and the condition of every other, even of the desire of happiness. Under these circumstances, there is nothing inconsistent with the wisdom of nature in the fact that the cultivation of the reason, which is requisite for the first and unconditional purpose, does in many ways interfere, at least in this life, with the attainment of the second, which is always conditional, namely, happiness. Nay, it may even reduce it to nothing, without nature thereby failing of her purpose. For reason recognises the establishment of a good will as its highest practical destination, and in attaining this purpose is capable only of a satisfaction of its own proper kind, namely, that from the attainment of an end, which end again is determined by reason only, notwithstanding that this

may involve many a disappointment to the ends of inclination.<sup>249</sup>

Kant introduces the concept of duty as the primary example or concept. By duty, Kant means the moral ought.

In order to do this we will take the notion of duty, which includes that of a good will, although implying certain subjective restrictions and hindrances. These, however, far from concealing it, or rendering it unrecognisable, rather bring it out by contrast, and make it shine forth so much the brighter.<sup>250</sup>

When we do what we ought to do rather than what we feel like doing, then we are acting from duty.

Morality appears to be for Kant that element in our life which urges us to do good rather than evil. To love and not to hate, to practice virtue rather than vice. In that we may willingly do so, because it gives us pleasure, the less we stand in need of a moral law. But when we ought to do something for which we have no inclination, then a moral command is needed. In those instances when we have no inclination for duty and yet do it, then it is that we receive what Kant refers to as moral credit. Kant offers us the proposition that,

An action done from duty derives its moral worth, not from the purpose which is to be attained by it, but from the maxim by which it is determined, and therefore does not depend on the realization of the object of the action, but merely on the principle of volition by which the action has taken place, without regard to any object or desire.<sup>251</sup>

Kant recognizes that it is impossible to determine whether someone acts purely from duty or whether there is also some hidden motive involved. Although one likes to hope that an individual's or group's motives are pure, nonetheless, one cannot be sure, and if moral worth should be determined by the motive, then the experience of the action will not give us a sure knowledge of the moral value of the action.

In fact, it is absolutely impossible to make out by experience with complete certainty a single case in which the maxim of an action, however right in itself, rested simply on moral grounds and on the conception of duty. Sometimes it happens that with the sharpest self-examination we can find nothing beside the moral principle of duty which could have been powerful enough to move us to this or that action and to so great a sacrifice; yet we cannot from this infer with certainty that it was not really some secret impulse of self-love, under the false appearance of duty, that was the actual determining cause of the will. We like then to flatter ourselves by falsely taking credit for a more noble motive; whereas in fact we can never, even by the strictest examination, get completely behind the secret springs of action; since, when the question is of moral worth, it is not with the actions which we see that we are concerned, but with those inward principles of them which we do not see. <sup>252</sup>

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According to Kant, everything in nature operates according to principles or laws. Those rational beings who can conceive of the idea of law and act on principle have the ability we refer to as the will. This requires reason, and therefore the will and practical reason are generally considered the same ability. An imperative is an expression

of a command of reason. Commands of reason result from a rational awareness of an objective principle.

All policy, whether it be individual or public, reflects some law. Everything that occurs follows some law of nature. The laws of nature are descriptive law. The laws of man are prescriptive. Knowledge of law and compliance with law are linked by the will which is associated with practical reason and is our capacity to comprehend principles and take appropriate actions. Sometimes we act in violation of one principle in order to adhere to another. This reflects some inconsistency in our principles.

The intent of our principles is to assist us in obtaining our goals. It is the natural goal of man to attain happiness. According to Kant, reason alone cannot lead us to happiness because we cannot control the vicissitudes of life. However, even though we may not achieve this natural goal, we can achieve our moral goal, or "rational purpose" which is to be "worthy of happiness."

We run into difficulty when our inclination prompts us to choose a means for attaining happiness that is inconsistent with what our reason represents as necessary for being worthy of happiness.

Finally, there is an imperative which commands a certain conduct immediately, without having as its condition any other purpose to be attained by it. This

imperative is categorical. It concerns not the matter of the action, or its intended result, but its form and the principle of which it is itself a result, and what is essentially good in it consists in the mental disposition, let the consequence be what it may. This imperative may be called that of Morality. <sup>253</sup>

Kant makes a comment in applying his principles of rational judgment in the search for happiness applicable specifically to the parenting of children.

Since in early youth it cannot be known what ends are likely to occur to us in the course of life, parents seek to have their children taught a great many things, and provide for their skill in the use of means for all sorts of arbitrary ends, of none of which can they determine whether it may not perhaps hereafter be an object to their pupil, but which it is at all events possible that he might aim at: and this anxiety is so great that they commonly neglect to form and correct their judgment on the value of the things which may be chosen as ends.

There is one end, however, which may be assumed to be actually such to all rational beings (so far as imperatives apply to them, viz. as dependent beings), and therefore one purpose which they not merely may have, but which we may with certainty assume that they all actually have by a natural necessity, and this is happiness. <sup>254</sup>

When we feel that in order to gain happiness we must do some particular thing, the necessity of that action depends upon the nature of our desire. To be necessary, however, by virtue of reason, the action must be done as a result of our will to be worthy of happiness, whether or not happiness is actually gained. The act must be necessary on its own merits also, and we must will to do it because it is necessary.

The categorical imperative of Kant suggests that action may be categorically and unconditionally necessary regardless of our desires or inclinations. The value of the action is within the action itself which encompasses the motive for doing it. There is an unconditional and moral necessity in the command of the moral imperative.

There is, therefore, but one categorical imperative, namely this: act only on that maxim whereby thou canst at the same time will that it should become a universal law.<sup>277</sup>

Kant thus condenses the essence of his categorical imperative into the universal law which applies to everyone. Kant admonishes us to act on maxims that we would want to have as universal laws of nature; to treat others, whether directly or in our decisions which affect others as an end and not as a means; to act in such a way that we would want to live in a community governed by the principles we live by. How we view individuals is significant and determines the decisions that we make that affect them. Kant offers significant commentary on the relationships between individuals and society:

Rational beings, on the contrary, are called persons, because their very nature points them out as ends in themselves, that is as something which must not be used merely as means, and so far therefore restricts freedom of action (and is an object of respect). These, therefore, are not merely subjective ends whose existence has a worth for us as an effect of our action but objective ends, that is no other can be

substituted, which they should subserve merely as means, for otherwise nothing whatever would possess absolute worth; but if all worth were conditioned and therefore contingent, then there would be no supreme practical principle of reason whatever.<sup>256</sup>

Kant offers a rationale for his designation of human beings as subjects worthy of respect. He indicates that a rational being has intrinsic worth: the only absolutely good thing is the good will. Reason is the foundation of the good will, and, therefore, it has an intrinsic value. Human beings, because they are rational beings who are capable of reasoning, therefore have an intrinsic value. Therefore, every man, every human being, is an object having absolute value, because as a rational being, human beings are the foundation of their own good will, which is an absolute good. The worth of a rational being is not dependent upon having a good will, but rather because human beings are rational beings and, as such, can have a good will.

### Free Agency and Self-Determination

The moral authority of practical reason is founded in freedom. The concept of duty presupposes a freedom of choice. If there is true freedom of the rational will, then morality can have genuine meaning in practical law. Man would not have freedom if he was simply the pawn of his own

desires. People should freely determine their duties and choose to do them. Duties which are chosen are examples of free action.

The will is a kind of causality belonging to living beings in so far as they are rational, and freedom is a property of such causality in so far as it can be efficient, independent of foreign causes determining it; just as physical necessity is the property that the causality of all irrational beings has of being determined to activity by the influence of foreign causes. <sup>257</sup>

Kant's proof of freedom as an a priori principle is based upon the relationship of rationality to a free will and man's rational being and therefore moral agency. This is the basis of his proof, because free will is necessarily related to rationality, and thus Kant proves the universality of free will and that every human being is subject to a moral law.

Now I say every being that cannot act except under the idea of freedom is just for that reason in a practical point of view really free, that is to say, all laws which are inseparably connected with freedom have the same force for him as if his will had been shown to be free in itself by a proof theoretically conclusive.

Now I affirm that we must attribute to every rational being which has a will that it has also the idea of freedom and acts entirely under this idea. <sup>258</sup>

Kant sees freedom of will as a necessary and fundamental condition for moral life. Being able to choose independently of the laws of natural causality, we are able

to meaningfully be judged subject to the moral command of reason.

## CHAPTER 5

### RIGHTS, DUTIES AND OBLIGATIONS IN THE FAMILY AND SOCIETY IN A CONTEMPORARY CONTEXT

An elucidation of the conflicts which arise between society and the parents of handicapped children has thus far been presented from the perspective of the parental perception of those conflicts. It is proposed that a foundation for judgment in the attempt to resolve parental and societal differences is to be found in Immanuel Kant's essay, Fundamental Principles of the Metaphysic of Morals. A summary of pertinent portions of the essay therefore followed the presentation of the problem as seen by the parents of handicapped children. Kant's guiding principles to be honored in human relationships, both public and private, are specifically applicable to the relationship between society and the parents of handicapped children because Kant's principles are formulated from a thorough examination of what constitutes rights and what constitutes obligations in the conduct of human affairs.

The issues joined in parental-societal conflict vis a vis the handicapped child also devolve from definitions of

the rights and obligations of each of the three parties to the conflict. Although differences may be the result of a hurtful attitude, ignorance, anxiety, frustration, pride, or the inability to cope with an apparently overwhelming situation, what perpetuates those differences is the failure of one of the three to fulfill the obligation to treat the other with the kindness and understanding necessary for an alleviation of the pain of the conflict. This is the failure to have what Kant calls "good will," the "indispensable condition."

The rights and obligations of children, parents, and society must be determined on the basis of principles established through sound reasoning and a valid perception of natural law. Kant's work provides a rationale for the formulation of duties and obligations based upon the paramount value of good will. But how can this formulation be translated into maxims applicable to the conflictive situations that the families of handicapped children and society find themselves in? An examination of the concept of children's rights may help in finding an answer to this question.

What exactly is a "right?" In speaking of the rights of children, parents, and society it is helpful to adopt the approach taken originally by W.N. Hohfeld, namely, that of "right relationships" or the relationships between right

holders and right regarders.<sup>260</sup> One must also sustain an awareness that a right may be at one time held by one and regarded by another and at another time regarded by the previous holder and held by the previous regarder. There may be mutual rights, as is often the case when fathers and mothers share rights to determine the upbringing of the child. There may be exclusive rights which an individual does not share with others because those rights pertain to outcomes that affect only the one person. But what affects any one individual will eventually affect society unless that individual lives alone on an island. The concept of solely individual rights is, then, subject to qualification.

Hohfeld divides rights into five groups: claims, which are also referred to as rights "in the strictest sense" of the term; liberties (or privileges); powers; immunities; and mixed rights. The claim is defined as a right to the assertion by one individual (the right holder) of the demand on another (the duty bearer) to forbear. Thus,

should the claim be in force or exercised, and the act of forbearance not done, it would be moral (or legal, in the case of legal right), other things being equal, to use coercive measures to extract either the specific performance (i.e., the act of forbearance claimed), or compensation in lieu of it."<sup>261</sup>

Children's claims (or rights "in the strictest sense") are defined according to Hohfeld's reading of societal

consensus as the right to expect of their parents or guardians the necessities of life: a home, nourishment, education, medical care, and in some sectors of society, "a proper moral climate." Defining the necessities of life more specifically is difficult. That which we call a "home" might be anything from a Navajo hogan in the Arizona desert (and there are many of these native American homes which are filled with love, tradition, good nutrition, and appropriate parental discipline) to the most fashionable of mansions (and some of these offer little more than junk food and a schizogenic environment). What constitutes adequate "nourishment" may be physiologically determined, but the availability of the best of foods does not necessarily guarantee the healthiest of diets. Bulemia and anorexia are more common among the affluent than among the poor, and overeating, with all of its psychological consequences, is found in every socioeconomic stratum. There is no clearly indisputable definition of "proper medical care." Although the courts will generally rely on expert testimony in determining what is proper, parents may believe that they have the right to provide alternatives to modern medicine such as folk medicine or faith healing. Even among board-certified medical specialists there is controversy concerning the appropriateness of many surgical and therapeutic interventions, particularly in the

treatment of the handicapped infant. Education has often been the subject of dispute between parents and the state. One need only recall the many suits brought against the Amish people because of their methods of education, which society seemed to find objectionable. At the same time it is even more important to recall that the Amish people are now vindicated through the same judicial process which subjected them to the suits they contested. Even the education offered in major metropolitan school systems has come into question. And when we try to reach an agreement on what constitutes a "proper moral climate" a consensus seems more difficult to find than with any of the other necessities of life deemed the legal right of children to claim.

Out of respect for the individual rights of lesbian mothers, homosexual fathers (ten percent of all homosexuals are parents) utopian communal "groupies," and even those judged to be patently "criminal elements," American society has shown itself reluctant to judicially curtail the right of parents to raise their children as long as the parents are not physically abusive. And it is true that children are known to have been reared under the most unusual of moral circumstances and yet have grown up to be productive citizens. This fact does not, of course, silence the moral concerns which society frequently voices in many forums. We are nonetheless loath to interfere with the sanctity of

the home or to curtail individual rights. But we have more recently become increasingly aware of the devastating and long-term harmful effects that emotional abuse and sexual misconduct in the home have on children. The courts have moved to protect children, and laws have been enacted which address the rights of children to be free from such assaults upon their psyches. Unfortunately, the assault must generally be blatant and recognizable to those outside the home before protective measures are undertaken.

Parents may also have claim rights with regard to their children. They may have a claim upon society for certain provisions that families alone would be unable to provide. This may be particularly true in the case of the handicapped child. It is certainly typical of the adopted handicapped child, in which case the support of the child may be subsidized by the state. Parents may have claim rights to the respect of their children. Although respect is hardly enforceable by the laws of society, the laws of the family may demand it. Parents certainly have the right to expect the same protection of the law if they are in conflict with their children as they would if they were in conflict with any other adult member of society.

Society may have a claim upon parents with regard to their children. Neighbors may complain if babies cry too much. Society may insist, out of concern for the economic

productivity of the whole community, that parents train their children and educate them so that they will be able to contribute to the community later in life. Parents are expected to prevent the delinquency of their minors and can be held accountable for damages their children may inflict. Society may express claim upon children for certain behaviors and conformity to certain expectations.

Houlgate differentiates between claim rights that are "positive" and claim rights that are "negative."<sup>262</sup> The former are the rights to positive actions on the part of other persons and the latter are the rights to demand other persons' omissions or forbearances. Positive rights impose on others a duty or obligation to provide or protect. Negative rights include such things as privacy, freedom from abuse and the right to an undamaged reputation.

Another formulation of the claim right is that of Lawrence Becker's "capacity claim" which he describes as calling attention to one's capacity or the assertion of one's competence to perform some function of life as in the meaning that they feel they should have such rights as adults have and they wish to assert their capacity to be regarded as having such rights.<sup>263</sup>

Liberties, also called privileges by some, imply no duties on the part of others, but rather freedom from duties for the holder of the liberty and freedom from the

claim rights of others on those with the liberties. Liberties may be secured by claim rights to hold the liberties, but such claim rights are separate from the liberties themselves.

Powers represent those rights which one may hold in relationship to others to assert in making just demands or to require certain actions or non-actions of another. As Becker puts it, "the existence of a power right is the existence of a state of affairs such that one person (the right holder) may morally (or legally) alter at will some of the rights, duties, liberties, powers or immunities of another person (the liability bearer).<sup>263</sup>

Immunities represent freedoms from control of others relative to a legal relationship. Children are, for example, immune from the willful alteration by their parents or custodians of their claim rights. This immunity also constitutes a lack of power or an inability on the part of others.

Mixed rights are those which combine other rights such as the combination of liberties, powers and capacity rights (as in the case of the right to marry). Houlgate discusses the importance of due process as an example of a mixed right:

It consists of such legal rights as the right to be assisted by counsel, to a speedy trial, to a public trial, to confront opposing witnesses, to a trial by

jury, to be free from double jeopardy, and to non-self-incrimination. Not only is the right to due process a mixture of rights, but some of the specified rights are combinations of kinds of rights. Thus, we find not only a liberty (the right to confront opposing witnesses), an immunity (the right to be free from double jeopardy), and claims (the right to a speedy trial, the right to a public trial), but also a right that is a mixture of liberty and claim (the right to non-self-incrimination).<sup>261</sup>

Consideration of rights on the basis of the processes by which they are justified leads to distinctions between moral and legal rights. When a right is upheld on the basis of a recognized statute, it may be referred to as a legal right. However, such rights are not universal and will vary according to the legal system appealed to. Even within legal systems there may be debate over the justification of rights. A legal realist may hold that only those rights which are enforced or upheld by the courts are indeed rights. Others may hold that all rights which they believe the legal system ought to recognize under natural law are indeed rights. A contemporary legal positivist would proclaim as rights those which are actually "recognized, either implicitly or explicitly, by the legal system."<sup>262</sup>

Those rights that are justified by an appeal to moral reasoning and are considered separate from any statutory presence are moral rights. There will always be debate and differences of opinion both as to what these rights are and as to what process of reasoning supports the moral argument. Some may take a utilitarian approach and consider

moral rights those which are in the best interest of the greatest number. Others may follow arguments on the basis of a different concept of justice, or prudence, or fairness.

Human rights are those rights which are accepted as moral rights "held equally by all human beings unconditionally and unalterably."<sup>262</sup> Such rights may also be referred to as natural rights.

In any discussion of rights, whether they be children's or adults', it is important to establish the basis of the right being examined and to determine whether it is grounded on a legal statute or is simply accepted as universal moral law. Rights always have cultural and societal foundations. If one accepts that there are universal human rights that apply equally in principle to all human beings or that there are laws of life which originate with God or a power beyond human power, then it is important to recognize that human beings are not universally in agreement as to the definition or application of such rights either in theory or in practice. There are, however, some rights which, despite cultural differences in the way they are expressed seem to be recognized by a great majority of all the peoples on this earth.

## Basic rights of all children:

The basic rights of all children are declared in the United Nations Declaration of the Rights of the Child in these words: "Mankind owes to the child the best it has to give."<sup>264</sup> But there is little agreement as to how mankind should fulfill that debt or what mankind is willing to sacrifice in the process of fulfilling it. The United Nations document adopted by the General Assembly in 1959 reflects previous documents formulated by the International Union for Child Welfare in 1923, adopted by the League of Nations in 1924, and revised in 1948. It recognizes attitudes shared by many cultures and many nationalities regarding the rights of children.

The basic principles outlined in the document encompass areas of non-discrimination; securing rights to develop in health, with freedom and dignity for both child and parent; the right to appropriate education including special consideration for the handicapped; the right to protection from harm or neglect, exploitation or premature employment; and the right to be free of unjust servitude either physical or mental.

Every aspect of the United Nations declaration applies equally to those children who are born with handicaps, or who develop handicaps later in life. Special attention is

also given specifically to the handicapped child or those "physically, mentally, or socially handicapped." Such declarations are worthy expressions of worldwide societal consensus. But declarations do not always guarantee practices that reflect their principles. Actual societal behavior in a given nation may be quite different from that nation's political appearance and the image projected by a leader who is aware of world public opinion.

The United Nations declaration of the rights of the child offers a formulation of moral and political thought and reflects traditions grounded in the religions of the predominant cultures of the modern world. Many of the expressions are given in open-ended terms, subject to interpretation such as "special protection," "in a healthy and moral manner," or "tender years." The principles also imply that those who are responsible for the children are enabled by an adequate economic capability. The declaration does specify that it is preferable for children to grow up under the care and responsibility of parents, and it assigns accountability to all individuals, organizations, and governments to recognize and strive for the observance of the principles "by legislation and other measures progressively..."

Finding the means for applying to governmental processes the principles enunciated in the United Nations

Declaration of the Rights of the Child necessitates an appeal to the more fundamental principles applicable in human relationships and individual morality, in the city, state, or national government, and in the rules that families adopt for their own governance. We turn to Kant's concepts outlined in the Fundamental Principles of the Metaphysics of Morals in our search for these means.

## CHAPTER 6

### THE CONCEPT OF PARENTING FROM A KANTIAN PERSPECTIVE

Kant addresses the issue of parent-child relations in his Principles of Private Right<sup>264</sup> and places the family as a legally necessary entity among the duties of man.

From the Duty of Man towards himself--that is, towards the Humanity in his own Person--there thus arises a personal Right on the part of the Members of the opposite sexes, as Persons, to acquire one another really and reciprocally by Marriage.<sup>266</sup>

It is presumed, based upon such a union that offspring will naturally follow in the course of human events and thus an associated duty.

In like manner, from the fact of Procreation in the union thus constituted, there follows the Duty of preserving and rearing Children as the Products of this Union.<sup>266</sup>

Kant then proceeds to a congenital Right of the child to expect parental accountability based upon the child's incapacity to take care of himself. This is natural Law grounded in the Personhood of the individual.

Accordingly Children, as Persons, have, at the same time, an original congenital Right--distinguished from

mere hereditary Right--to be reared by the care of their Parents till they are capable of maintaining themselves; and this provision becomes immediately theirs by Law, without any particular juridical Act being required to determine it.<sup>265</sup>

The next step is recognition of personal "Freedom", which is not the product of biological procreation alone.

For what is thus produced is a Person, and it is impossible to think of a Being endowed with personal Freedom as produced merely by a physical process. And hence, in the practical relation, it is quite a correct and even a necessary Idea to regard the act of generation as a process by which a Person is brought without his consent into the world, and placed in it by the responsible free will of others.<sup>265</sup>

Thus, children, because they are brought into this world without consent, according to Kant, must be so reared by their parents that they learn the nature of their existence through respect for their individual freedom.

This Act, therefore, attaches an obligation to the Parents to make their Children--as far as their power goes--contented with the condition thus acquired. Hence Parents cannot regard their Child as, in a manner, a Thing of their own making, for a living being endowed with Freedom cannot be so regarded. Nor, consequently, have they a Right to destroy it as if it were their own property, or even to leave it to chance; because they have brought a Being into the world who becomes in fact a Citizen of the world, and they have placed that Being in a state which they cannot be left to treat with indifference, even according to the natural conceptions of Right.<sup>266</sup>

Although Kant's view does not reflect any concept of premortal decision-making or choice, but rather birth

"without consent", he does ascribe innate rights to offspring by virtue of the personhood and citizenship in society with which each individual is endowed at birth.

We cannot even conceive how it is possible that God can create FREE Beings; for it appears as if all their future actions, being predetermined by that first act, would be contained in the chain of natural necessity, and that, therefore, they could not be free. But as men we are free in fact, as is proved by the Categorical Imperative in the moral and practical relation as an authoritative decision of Reason; yet reason cannot make the possibility of such a relation of Cause to Effect conceivable from the theoretical point of view, because they are both suprasensible. All that can be demanded of Reason under these conditions, would merely be to prove that there is no Contradiction involved in the conception of a CREATION OF FREE BEINGS; and this may be done by showing that Contradiction only arises when, along with the Category of Causality, the Condition of Time is transferred to the relation of suprasensible Things. This condition, as implying that the cause of an effect must precede the effect as its reason, is inevitable in thinking the relation of objects of sense to one another; and if this conception of Causality were to have objective reality given to it in the theoretical bearing, it would also have to be referred to the suprasensible sphere. But the Contradiction vanishes when the pure Category, apart from any sensible conditions, is applied from the moral and practical point of view, and consequently is in a non-sensible relation to the conception of Creation.

The philosophical Jurist will not regard this investigation, when thus carried back even to the ultimate Principles of the Transcendental Philosophy, as an unnecessary subtlety in a Metaphysic of Morals, or as losing itself in aimless obscurity, when he takes into consideration the difficulty of the problem to be solved, and also the necessity of doing justice in this inquiry to the ultimate relations of the Principles of Right. <sup>267</sup>

What are the duties of parents from Kant's point of view? Clearly there is a right to be the primary rearing party. Some parents might question why anyone would want to secure a legal right to perform such a thankless job. And we should remember that Kant had neither a wife nor children. Nonetheless, Kant's vision is universal and he sees the importance of the commitment of parents to children in the continuum of human society. The Duty of parents is prescribed because of the inability of children to provide for themselves. Education is specifically enumerated as a duty of parents in order to bring the child into a position of self-support.

#### The Rights of the Parent

From the Duty thus indicated, there further necessarily arises the Right of the Parents to THE MANAGEMENT AND TRAINING OF THE CHILD, so long as it is itself incapable of making proper use of its body as an Organism, and of its mind as an Understanding. This involves its nourishment and the care of its Education. This includes, in general, the function of forming and developing it practically, that it may be able in the future to maintain and advance itself, and also its moral Culture and Development, the guilt of neglecting it falling upon the Parents.<sup>267</sup>

When the child reaches an age at which he can legitimately support himself, then the parent's right to command, according to Kant, is terminated. Those who have raised children to adulthood know well how difficult the

transition to self-sufficiency can be in spite of much training and preparation. One must assume that those children who never attain an age of accountability because of mental retardation or incompetence may remain under the control of their parents and never attain the emancipation on the same basis as other children.

All this training is to be continued till the Child reaches the period of Emancipation (emancipatio), as the age of practicable self-support. The Parents then virtually renounce the parental Right to command, as well as all claim to repayment for their previous care and trouble; for which care and trouble, after the process of Education is complete, they can only appeal to the Children by way of any claim, on the ground of the Obligation of Gratitude as a Duty of Virtue.<sup>268</sup>

The children's duty to parents after achieving emancipation is, according to Kant, of less weight and power legally, being a "Duty of Virtue" on the part of children as compared to the "congenital Right" which obligates parents to provide for their children. Children have claim upon their parents while in their years of dependency, but parents do not have claim upon their children when in their years of dependency on the same basis, i.e. "congenital right." Parents may claim that children have a duty to them "on the ground of the Obligation of Gratitude." This is a "Duty of Virtue" and not a "congenital right." For example, if a child is abusive to a parent, as long as the child is in his years

of dependency the parents have a duty to provide for and care for the child. If, on the other hand, the parent is abusive to the child, then the child could be relieved of any duty on the basis of gratitude to care for the parent in old age.

Children, although not the property of parents, are their possession and as such their "subjects." Thus parental rights are described as "personal right(s) of a real kind."

From the fact of Personality in the Children, it further follows that they can never be regarded as the Property of the Parents, but only as belonging to them by way of being in their possession, like other things that are held apart from the possession of all others and that can be brought back even against the will of the Subjects. Hence the Right of the Parents is not a purely Real Right, and it is not alienable (jus personalissimum). But neither is it a merely Personal Right; it is a Personal Right of a real kind, that is, a Personal Right that is constituted and exercised after the manner of a Real Right.<sup>269</sup>

"Real Rights" refer to power over concrete things, which children are not. Nonetheless, not having gained sufficient ability to have full power over themselves, children may be administered over with a similar degree of control as would be applied to concrete possessions.

It is therefore evident that the Title of a Personal Right of a Real Kind must necessarily be added, in the Science of Right, to the Titles of Real Right and Personal Right, the Division of Rights into these two being not complete. For, if the Right of the Parents to the Children were treated as if it were merely a

Real Right to a part of what belongs to their house, they could not only appeal to the Duty of the Children to return to them in claiming them when they run away, but they would be then entitled to seize them and to impound them like things or runaway cattle.<sup>269</sup>

Children gain their freedom from the command of their parents upon reaching the age of natural majority. By the same token parents regain their freedom from obligation to their children at the same time.

The Children of the House, who, along with the Parents, constitute a Family, attain majority, and become MASTERS OF THEMSELVES (majorennnes, sui juris), even without a Contract of release from their previous state of Dependence, by their actually attaining to the capability of self-maintenance. This attainment arises, on the one hand, as a state of natural majority; with the advance of years in the general course of Nature; and, on the other hand, it takes form, as a state in accordance with their own natural condition. They thus acquire the Right of being their own masters, without the interposition of any special juridical act, and therefore merely by Law (lege); and they owe their Parents nothing by way of legal debt for the Education, just as the parents, on their side, are now released from their Obligations to the Children in the same way. Parents and Children thus gain or regain their natural Freedom; and the domestic society, which was necessary according to the Law of Right, is thus naturally dissolved.<sup>270</sup>

Children in this majority or other individuals who may wish to work and abide in a household, may, according to Kant, enter into a contract with the master of the house. But their relationship relative to duties and obligations is limited to the terms of the contract.

Kant describes familial relationships in terms that seem legalistic matters of right, duty, and obligation. This pattern, however, does not necessarily exclude the full range of emotional possibilities that families may enjoy.

The key elements in Kant's discussion of parent and child relationships are the principles of freedom by virtue of reason and the independence of the individual attained through maturation and training by parents. Children are born with the right to attain their majority with the assistance of parents who are obligated to clothe, feed, house, and educate them.

But what is the good of the family structure? For what purpose, ultimately, does Kant see this particular design pursued? Although he begins his discourse on parent-child relations by stating the necessity of rearing children by virtue of the natural processes of life and regeneration, there is a distinction given to man which separates him and the society of his family from all other species. That quality is reason which permits freedom through the exercise of agency. The imperative which compels man to choose right principles to govern himself within the context of that family structure and to seek willingly the welfare of his children is reflected in a desire for happiness which, according to Kant, is not a guaranteed state in life. The thrust of human effort, however, should

be directed toward that goal which is indeed attainable according to Kant, namely worthiness to be happy.

The highest good (summum bonum) attainable in life which can be comprehended through moral reason is "worthiness to be happy."

## CHAPTER 7

### AN ANALYSIS OF THE CASES PRESENTED FROM A KANTIAN PERSPECTIVE

After reviewing the literature of conflict between families and society relative to the rearing of handicapped children, presenting a series of cases and discussing their related conflictive issues, presenting a brief synopsis of a philosophical approach to human relations and the Kantian view of the family, attention is now focused on a re-examination of the issues posed by the cases presented in light of the Kantian perspective. The cases, the perspectives from which they arise and find expression, and the positions taken by the parties involved reflect substantial moral dilemmas. By superimposing a framework constructed of Kantian principles over these cases, a view towards resolution of the apparent conflicts can be elucidated.

In the realm of socio-legal issues this work began with a presentation of conflicts which arise between parents and professionals. Clearly, a societal consensus with regard to the appropriate roles of parents and society

would alleviate much of the conflict. Kant does not provide us with specific details of parental and societal roles, but his principles offer direction sufficient to understand his view and expectations of children and parents.

Kant expects that people will have children as a matter of course and human nature and that children will obtain, by virtue of their person, freedoms. Parents should accept their responsibilities to provide for and nurture their children until their majority.

The first conflict discussed in the socio-legal issues section dealt with child abuse. From a legal perspective relative to the handicapped child abuse may take many forms: physical, emotional, medical, etc. The question at hand is what is the proper role of society in intervening on behalf of children and in opposition to parents when an abuse is suspected. An examination of Kant's expressions regarding familial affairs would lead one to place primary authority in the hands of parents. Nonetheless, Kant points out the requirement for parental recognition of children's rights to expect parental accountability based upon the child's incapacity to take care of himself. This is defined as natural law grounded in the personhood of the individual. Thus Kant would support legal intervention on behalf of the child in recognition of a child's rights as an individual. However, grounds for usurping parental

authority would have to be based on such a severe compromise of the child's rights that the benefit of parental authority would be negated.

The concept of a foster home placement for children who are abused would probably not be out of the realm of possibilities from a Kantian perspective. Foster parents would necessarily bear the same relational responsibility toward a child as natural parents would. Again, as in the case of biological parents, the child is placed without necessarily his own consent into a situation, and therefore it becomes the responsibility of the foster parents to respect the rights of the child. Kant suggests that parents regard their child, not as a "thing of their own making," but rather a living human being endowed with freedom.

With regard to respect for free will and the importance, from a Kantian perspective, of the development of human will it would seem essential that parents facilitate opportunities for their children to negotiate to whatever extent possible with the world around them. Children, however handicapped, are potential parents. Their capacity to make right decisions and set examples for their children to make right decisions will depend upon the opportunities they have to reason and "think through" the dilemmas life presents them.

Placing the primary responsibility for the rearing of children upon the shoulders of parents, Kant provides as a claim right of children the necessary attentions of their parents. This claim right proceeds from the incapacities of the child to provide for himself, and the personal freedom inherent in the personhood of the child, the child having come to earth, according to Kant, without his consent and as the result of a choice made by parents which is commensurate with the nature of the human species.

Thus a trust is established wherever parents are held accountable and children may grow up in the security of expectations that their welfare will be responsibly taken care of by their parents. When that trust is broken by parental abuses of children, then the violation will bear deep psychological consequences.

A Kantian approach to the issue of parent-child trust would require absolute integrity and an honoring of the commitment entrusted in the parent. Children would anticipate their right to the honest behavior of their parents toward them and society would anticipate that parents would honor this trust, as children are entrusted to them by nature (or by God).

Children also would be expected, by parents and by society, to act honestly towards their parents and towards society beyond the realm of the family to the degree that

they have attained a level of accountability for their actions.

In the discussion of child abuse cases covered in this work the question of judgment and intervention where abuse or neglect is suspected by society is brought up. What authorities should appropriately be assigned to society and what would, from a Kantian viewpoint, be the appropriate role of the various social services and judicial institutions in cases where abuse or neglect is suspected?

Kant seems to have held little special regard for the "social service" institutions of his day which were represented primarily by churches which worked in combination with political authority. Nonetheless, if the rights of children which are naturally theirs as human beings dependent upon the care of their parents such as life, or nourishment, would be violated, a Kantian approach would sustain some intervention. However, the latitude of parental authority would probably encompass a greater scope from a Kantian perspective than it does in modern American society.

A "least inhuman" invocation of the law, adjudication and intervention as recommended by Goldstein, et al., would find support in a Kantian attitude toward respect of individual freedoms. But these freedoms of parents and of children should not be compromised. The pursuit of parental

freedoms should not compromise the rights of children. Parents do not have a right to be "free" of their duty toward their children. Children were viewed by Kant as having rights as potential free and independent persons. Until they reached an age of majority, their freedoms were limited by their dependency upon their parents.

Today, where there is clear evidence of child abuse to the degree that the health and welfare of a child are compromised, then intervention generally results in some form of placement of the child protected from the abusive parent. In Kant's time, parentally-abused children were not removed from their families, but where families were unable to feed or care for a child or when a mother wished to give up her child, churches did take responsibility to operate orphanages. Because the church and state were not separated in Prussia, it would be inappropriate to distinguish between the two with reference to orphan care. Then, as today, it was clear that such institutions were not adequate substitutes for families.

Here we are concerned with principles, however, and not history. Therefore, a Kantian view with regard to parental obligations and authority would apply equally to biological parents as it would to surrogate parents.

### The Case of the Vulon Children

Proceeding from a sense of duty, the personnel of the state intervened in the interest of the children. However, their ignorance of the actual circumstances of the incident led them into a course opposite to the best interests of the children. The judge in this case affirmed the free will of the parents and hence their liberty to care for their children as they felt appropriate.

### The Case of Miss Shay

Clearly an overzealous social worker was confused, and she was supported in her confusion by unclear statutes about what appropriate state interests are in the welfare of children. The Kantian principle of free agency was violated to the detriment of the mother-child relationship.

### The Case of in re Pogue

Here a court intervened to protect the life of a child but preserved the agency of the mother with regard to her own welfare. The "maxim" of the mother was that the preservation of her life and of her child was not as important as obedience or duty to religious principles

which precluded a blood transfusion. The argument of the judge respected the mother's maxim as it pertained to herself but not as it affected the child. It was the judge's decision that the child's agency would be violated if his life were not preserved.

Kant provides a specific example in his discussion of maxims which may be applied to this case. He finds the maxim of "I must try to live as long as possible" grounded in a good will moral foundation and the maxim of "When my life becomes intolerable I will commit suicide" reflecting personal inclination but not impositions on others.

The mother in the above case was not actively attempting suicide, but was accepting a suicidal course of events as preferable to the violation of what she felt was a higher moral imperative and therefore an intolerable life.

Kant, in his example, does not seem to take into account that a suicide may indeed impose or inflict damage upon others such as children left behind.

### Medical Neglect

When parents refuse to accept medical treatment for their handicapped children, as in the case commented on by Duff and Campbell, their actions from a Kantian point of

view lack good will and cannot be supported by natural principles of agency. The motives of the parents may, at first glance, seem laudable, wanting to protect the children from having imperfect lives, but in the final analysis, one generally finds that the parents' motive for this action is based upon self-interest. Certainly the basic Kantian principle of acting out of duty to right principles rather than out of inclination is not fulfilled by parents who allow their handicapped children to die. There would be greater moral worth in preserving the life of the child even though it means hardship for both parents and child, and such a course would reflect a true Kantian response to a sense of duty.

In the case of Kevin Sampson a Kantian viewpoint would suggest the freedom of the child to express his view and the authority of the parent to determine the proper course for the welfare of the child should be sustained. However, parental authority would not qualify the parent to insist upon the fatal neglect of the child, as in the case of *Iafelice v. Zarofu*.

"Wrongful Life"

"Wrongful life" is a concept inconsistent with the free-will principles which lie at the foundation of Kantian philosophy. The term "wrongful life" implies that a judgement is made by others (parents or society) as to the value of a life which, in Kant's view, would have a sovereign right to self valuation at least at an age of majority.

A necessary component of Kantian free-will is the rational capacity of the individual. Some would argue that an individual who, as far as others can determine, never attains a state of rationality due to retardation, would not qualify for respect as a sovereign individual. But neither do infants possess such apparent rationality, and we are compelled to respect their rights and understand that they have the potential to grow up and become rational individuals. In the case of retarded children, we may find their limited state in this life lamentable, but this should not negate the value of their existence.

Although Kant addresses rights of individuals from the perspective of an earthly existence, the argument that an infant has rights in view of the free-will capacity which is potentially within him could be applied to the retarded child or person who, in spite of an apparent lack of

potential for rationality in this life, cannot be denied the potentiality for rational existence in his eternal existence (if one accepts such a concept).

In the case of Renee Iafelice (page 85) the decision of the court upheld the protection of "life" without qualification, quoting, "it is life itself that is jealously safeguarded, not life in a perfect state."

#### The Ryan Thomas Case

The case of Ryan Thomas poses a dilemma which may have had some parallels in Kant's time. Certainly, infectious diseases were a familiar problem and the isolation of individuals suspected of carrying infectious diseases was a common practice. Whether for leprosy, the plague, or tuberculosis, society was familiar with the need to protect citizens from the spread of infection. The question in Ryan's case is whether his behavior would cause his infection to spread. Clearly, community reaction and fears of perceived potential threats were factors. A Kantian view would preserve the freedom of the child to enjoy the benefits of society provided it did not cause undue risk to the community.

Ryan had AIDS and his situation in school created a conflict between his parents and his school district

regarding his isolation which was felt by his parents to be unjustified. The court ruled in favor of the parents.

A Kantian approach to this situation would respect the right of the family to pursue obtaining a public education in a fair and equitable manner. Naturally, the interests of the community are not to be overlooked. But, since there was no established risk to the community in spite of prejudices regarding the infection in question, the ruling could seem consistent with a Kantian approach, based upon Kant's upholding of parental rights.

#### Johnson v. Sullivan

The case of Johnson v. Sullivan would clearly have found resolution through a Kantian perspective regarding the rights of parents to determine the welfare of their children. For physicians to play "God" in selecting those whom they would treat based upon social criteria would fly in the face of true social justice which was so much a part of romantic era philosophy. Parents and society, according to Kant, cannot regard their children as "things of their own making," but rather, "being(s) endowed with Freedom." "Nor, consequently, have they a right to destroy it as if it were their own property, or even to leave it to chance." Thus we see that it behooves both parents and society to do

what is medically necessary for children according to the views expressed by Kant.

Here we see parents attempting to obtain the best possible medical treatment for their handicapped children free from arbitrary determinations on the part of the medical community as to the quality of the children's lives or the socioeconomic capacities of the parents which doctors felt compromised the viability of the children. The argument for their protection is similar to the one put forth in the case of Iafelice in that the quality of life should not be the determinant of decisions to treat or not to treat.

Certainly from a Kantian perspective, these children have rights, and the parents, who act as advocates in behalf of these children (unlike the Iafelice case) also have the right to expect fair treatment for their children.

### The Beckett Case

The case of Mary Katherine Beckett represents a situation in which society, due to technological advances, has the capacity to preserve and sustain life but not without prolonged dependency upon machines. Thus the normal human relationships between parent and child become interrupted and intellectual; emotional and social

development may be retarded. A Kantian perspective in the Beckett case would support the parental right to manage the welfare of their child at home and an obligation of the state to be non-discriminatory in its provision for financial support whether in the home or in an institution.

Discriminatory practices, or bureaucratic rulings which, although designed to protect the rights of some, may result in the detriment of others, are not specifically addressed in Kant's works. It is the basic principle of a good will which represents the ultimate criteria for goodness which would not permit the unfairness of discrimination.

A cognizance on the part of professionals who work in perinatal medicine nursing and social work of the potential magnitude of human sufferings which can result from the stress of dealing with the birth of a handicapped child could contribute significantly towards protocols which represent a humanistic good will and what Kant refers to as "being worthy of happiness."

### Conflicts Perceived by Parents

In the section on conflicts perceived by parents relative to the rearing of their handicapped children, the feelings and perceptions of the parents represented

manifest the complex variety of emotions parents feel towards their handicapped children and toward society.

The conflicts are between parents and society, between parents and children, between parents, and within the parents individually. The Kantian concepts of duty and good will can provide keys to the resolution of these conflicts.

Parents who respond in frustration and anger towards their children because they are presented with less than what they had hoped for in the physical or mental capacities of their children would benefit from a grounding in Kantian perspectives. To be worthy of happiness by virtue of having done one's duty motivated by a sense of good will is not an impossible goal. But many of the reactions of parents in frustration over their handicapped children reflect attitudes deeply ingrained in our society which tends to reject those who are "different". The parent is frustrated in several ways.

#### 1. Selfishly

- a. because the handicapped child is perceived as thwarting the parent's chances to obtain the things both tangible and intangible that the parent seeks;
- b. because the birth of the handicapped child may be perceived as a blight upon the otherwise unblemished family image. The parent fears that he or she will be

perceived by others as defective, having given birth to or sired something defective;

- c. because the parent is unable to gain the responsive love from the child that the parent wants and expects from a child;
- d. because the child will not be able to fulfill the dreams of the parents which the parents were unable to fulfill themselves, but hoped to vicariously experience through the child;
- e. because of self pity of the parent.

2. In sympathy for the child

- a. because the parent may discover that fair treatment for the child is not easily obtainable;
- b. because the parent feels inadequate to meet the child's needs;
- c. because the parent has pity for the child.

3. In relating to society regarding the child

- a. because the parent wants society to understand the child;
- b. because parents may want to prevent what has happened with their child happening to others;
- c. because parents may wish to become advocates for other children in the same category as their child;

- d. because parents may feel that others who have no handicapped child cannot understand what they are enduring.

These frustrations and anxiety-causing circumstances can result in experiences of anger and often the thwarting of the very goals the parents pursue. Other parents respond by uniting to meet an increased challenge. Nonetheless, it is difficult for parents to deal with problems that are rooted in societal attitudes. Often parental attitudes regarding handicaps are formed long before a handicapped child is born to a family.

Parental perceptions are strongly affected by societal attitudes and learned mores. Parental perceptions are also passed down to children, the parents having received the teachings of their own parents by precept and by example.

Parents who rear handicapped children must deal with the prejudices of society and the prejudices within themselves. An application of Kantian perspectives places accountability for children squarely in the hands of parents and does not qualify what the condition of the child may be except in terms of the dependence of the child upon the parents. A status of dependence may persist with handicapped children longer than with others and may even persist throughout the individual's life.

The role of society from a Kantian perspective would necessarily include a consideration for the welfare of others which is compassionate at least to that extent that people would want others to be compassionate towards them.

The maxim delineated in the categorical imperative which prompts us to choose as personal principles what we would want to have enacted as universal laws serves to encourage a formula in society of providing for the handicapped as we would want to be provided for when we are ourselves handicapped (as all who reach old age certainly become to some degree). This formula would also prompt us to compassionately serve neighbors who have handicapped children even as we would want to have our neighbors compassionately serve us when we have handicapped children.

But often the pain of prejudices is promulgated through ignorance rather than ill-will, and even the best intentioned words may fall on apprehensive ears to be interpreted as an offense. Here the Kantian categorical imperative works in a reverse or receivership mode as well. Not only should we be active in maxims which we would want to have as universal law, but we must receive, in the passive mode, the expressions and actions of others in a manner that we would want others to receive our actions regardless of how clumsy they may be.

This approach would not erase the need to correct the ignorance or the ill-will at the root of prejudices, but it would serve to dampen the consequences of offense taken where none is intended.

The next problem discussed in the parental perspectives section is that of guilt and the accompanying self-pity which is so destructive. In this context we have a valid application of Kant's argument of duty toward self to preserve life and not commit (emotional) suicide. Our "maxim has moral worth" according to Kant when we preserve our state of wholeness out of a sense of duty, "not from inclination or fear, but from duty."

The duty of the parent to discipline a child in spite of his handicap (page 107) will find support in a Kantian perspective. Nonetheless, Kant would give the parents freedom to spoil their handicapped children also. Kant specifies the duty of the parent to respond to the "original congenital Right--distinguished from mere hereditary Right--to be reared by the care of their Parents till they are capable of maintaining themselves."

On page 128 the issue of parental denial is discussed relative to its potential for conflict between family and society. Families may suffer under the critical orientation of social service professionals who view this denial as detrimental and make a concerted effort to "help" families

"see reality". The efforts of these professionals are laudable. At times they are certainly justified in their efforts to prevent any neglect that may ensue from parental denial of a child's defects and consequently his medical and educational needs.

On the other hand a certain degree of parental denial of a child's defects may be a positive force allowing families to move ahead in a positive, albeit sometimes unrealistic, approach to their child's life and potential for future achievement.

A Kantian approach would probably favor leaving the parents alone. Kant felt that parents were accountable and as such should be respected in the discharge of their responsibilities. However, Kantian "duty" must also be allowed the social service worker who is an agent of society responding on behalf of a legitimate authority to intervene in the interest of the child.

Siblings of handicapped children (page 128) offer an interesting problematic in the application of Kantian principles. Their growth and developmental progress may be deeply affected, positively or negatively by the introduction of the special needs of their handicapped sibling. How parents respond to the emotional needs of the sibling will affect, to a great extent, the direction of

the normal child's feelings about their handicapped brother or sister and handicapped children in general.

Kant recognizes "happiness" as the one end "which may be assumed to be such to all rational beings." This pursuit is the one which, of all the ends which the acquiring of skills may direct one to, constitutes a "natural necessity." Kant points this out in reference to the skills that parents attempt to assist their children in acquiring (page 235). If siblings of handicapped children are to be happy, they must have a clear understanding of their handicapped sibling's problems and needs so that there is no unrealistic threat perceived by the normal child and the self-image of the normal sibling is not undermined by his perceptions of how the handicapped nature of his brother or sister affects him.

On page 131 we move to the element of fear and the role it can play in the conflicts between parents of handicapped children and society. The situations and related cases deal with perceptions and realities, responses grounded in ignorance and fear of the unknown as well as fear of what is realistically within individuals fearing that they themselves are their worst enemy. Of all the fears of parents of handicapped children, the most common is the fear which focuses on the handicapping condition itself. The defect is the enemy. It has stricken

the child and may loom to strike again at children yet unborn.

Fear is not compatible with happiness. According to Kant, our goal in life is to be worthy of happiness. The primary condition for this worthiness is a good will. If we interpret fear to be a form of disdain either for self or for others, then the good will may come into question. To bring the good will of the parent into question seems unfair, however, because it is common to fear the unknown possibilities which the parent of a handicapped child with a genetic disorder must realistically face.

Kant offers the comfort of self assurance in good will even when "owing to special disfavor of fortune, or the niggardly provision of a step-motherly nature, this will should wholly lack power to accomplish its purpose." The value of the good will is intrinsic and cannot be detracted from.

Kant does not address directly the property of trust or faith which may well be a more direct process in dealing with fear. Generally, fear is overcome through understanding and confidence in a provident reality. But where fear is in reality an expression of selfish concerns for one's own potential losses and not the well-being of others, then Kant's admonition to duty motivated by good will is appropriate.

It is difficult to separate the person of the child from the person of the parent when examining the feelings of the parent for the child. Often expressions of concern for the welfare of the child, such as those on page 132 would appear compassionate. The possibility remains that the parent is expressing concern for the welfare of the child because the child represents a part of the person of the parent. When the parent says "I think I will die from hurting to think of his future without us," when contemplating institutionalization of a retarded child, we have to ask ourselves how much the parent may mean "I think I will die from hurting to think of our life without him," or "I think I will die from hurting when I think of my life (by proxy) in an institution. Only in sincere Kantian good will is the parent truly justified.

On page 135 we see how the apparently good motives of friends and professionals who speak out in ignorance of the impact their promptings can have upon a parent, can generate fear unnecessarily. This may provide a counter argument for Kant's good will approach. It appears in this case that the good will of the friend and professional who encourages the parent to institutionalize her child by painting a bleak prognosis backfires in the creation of

resentments, fears, and guilt feelings. Often the well-meaning friend is totally wrong in the assumptions made about the potential of the child.

According to Kant, even here, the "good will" itself remains unblemished. In spite of ignorance, lack of tact, and the hurt these behaviors may cause, the "good will" itself cannot be diminished in value. This does not, however, mean that the hurtful friend or professional would not benefit from a more informed application of their good will.

The example on page 139 of friends who helped a family with a sick child but resented it when the family attempted to pursue a normal life represents the insincere will which Kant cautioned against. It is not what one "performs or effects" that counts for Kant, but rather the motive behind it. The insincerity of friends who help but do not accept the pursuit of joy on the part of those they help reveals their true motives and will. Other examples follow on pages 140-142 demonstrating parental responses to the collective provisions of society in the interest of handicapped children which have the appearance of an insincere will to benefit them.

Anger is the subject of the next section. Here we must deal with parental anger as well as with those who may precipitate their anger. Let us deal with the anger first.

Kant finds the source of moral law in reason as opposed to experience. Much anger could be avoided if reason would prevail in those moments when parents are confronted with thoughtless but well intended remarks of others.

On the other hand, anger is offered in some of the cases presented as a positive force and a tool for parental ventilation of feelings that would be destructive if internalized. In the examples given on pages 143-145 conflicts are dealt with through the expression of anger which communicates forcefully the needs of families that feel backed into a corner emotionally.

If feelings of anger are destructive and if their expression results in contention and the destruction of motivation for good will then anger has no justifiable place in rational moral rule after the Kantian fashion. The pain which is avoided through angry ventilations is not resolved although it may seem temporarily salved. Unless the individual can deal directly with the cause of the pain and find a rational adjustment that does not hinder a good will toward self and others then the pain will eventually return and with it the anger which has also remained, unresolved with its cumulative effects and destructive nature.

Those whose words and behaviors precipitate the angry reactions of parents may benefit from a reevaluation of

their good will. If their will is truly good then an adjustment in its expression will follow their recognition of the consequences of their behavior and the perceptions of the handicapped child's parents.

### Siblings

Kant expressly defines parental accountability for the rearing of children but he does not name siblings specifically in his formula. Certainly siblings are under the same moral obligations as fellow citizens would be in Kant's proposal for the pursuit of happiness. Nonetheless, siblings do play a unique role and are affected in a unique manner in the family where a handicapped child is present.

The sibling of the handicapped child must often grow up side by side with the handicapped child. He may be a little younger or a little older. In either case his vision of himself as a person includes his perception of his family which represents his generative development. His handicapped sibling is a part of him and will have a profound effect upon him throughout life. This may be a blessing if it deepens his perspective and appreciation for the healthy body he has. It may be a hindrance if he sees himself defective by association. The power of an informed and rationally developed good will can go a long way

towards making a difficult circumstance one that builds character and leads to a well adjusted and happy existence.

Kant does not speak directly to human psychology in the sense that this field is appreciated today. Nonetheless, the behaviors he suggests as rational for productive human association based upon his concepts of right or true principles could easily be incorporated into a prescription for good psychological adjustment in the fashion of today's thinking. The idea of promoting a positive self-image of the sibling of a handicapped child and the understanding approach of parents who are considerate of all of their children's emotional needs are in harmony with a Kantian approach to human affairs.

It is also arguable that Kant's offerings to principles of human relations are too theoretical and not easily formulated into practical applications and specific behaviors. Because his principles are so general in nature and revolve around basic concepts of living "only on that maxim whereby thou canst at the same time will that it should become a universal law," it is not difficult to formulate almost any reasonable approach to human relations, family law, or even educational and medical ethics in such a way that one could declare them "Kantian."

It appears that Kant sought to find those universal laws which, through rational understanding, guide man to

his most fulfilling self, i.e. happiness. To be worthy of happiness is Kant's declared goal and he suggests that this is what all of us should strive for. But happiness is not defined and thus it is left to each individual to exercise that agency which Kant declares should be theirs by natural right and discover "true" happiness. In a pluralistic and tolerant society this is acceptable. Each individual is free to choose what constitutes for him "happiness." But it is likely that Kant had in mind a universally "real" happiness which each individual should have the agency to discover. The criteria for worthiness for that happiness were determined by universal truths and immutable laws for Kant.

Whatever the area of conflict we may examine, the resolution of that conflict requires the application of certain basic principles which are based upon universal truths. To whatever degree these truths are lacking, misunderstood or perverted, to that degree the resolution is retarded. The sibling, for example, who lacks good will toward himself or his handicapped brother cannot obtain happiness and freedom from the conflicts within him or between him and others in his family. This way of thinking is in stark contrast to the psychological approach that places the individual outside of the locus of control and, at least partially, estranged from the formulation of his

will. Environmental influences, the ecology of society, the control of the circumstances all "impact upon" the individual, and agency is, in a certain sense, compromised, in this psychological approach. It is doubtful that Kant would have accepted as much compromise of human agency as modern psychology allows for.

Certainly the circumstances described in the cases presented in this dissertation present dilemmas far beyond what was routine in the community of Kant's Koenigsburg. Nonetheless, if the principles he expresses are true, their value should be universally beneficial in any community in any age.

### Discrimination

On page 162 attention is turned to conflicts that have been addressed in case law between parents of handicapped children and society. The cases presented revolve around the issue of discrimination when minority handicapped children appeared to receive a different level of services than other children.

The root problem here seems to be the consideration of people's needs on the basis of their association with some identifiable group, i.e. skin color, language, cultural background, socioeconomic status, etc. rather than an

approach based upon an assessment of the individual. Even when measures were taken specifically to remediate the discriminations of the past and provide assurances for fair and equal treatment for all through racial quotas for entrance into special education, the result was a detrimental denying of services where children had real needs because children were being evaluated with their group affiliation in mind rather than their individual needs.

From a perspective of Kantian justice there seems to be no basis for discrimination on any grounds other than real and actual individual assessment. If the law an individual takes to be his own is only that which he would want as universal law for his neighbor, then a regulation which discriminates unfairly on the basis of perceived differences of no consequence relative to the matter being regulated would be inconsistent with fair and equitable justice.

On the other hand, if an individual's orientation was what is referred to today as "racist" or, in other words, protective of that which is racially, ethnically, or linguistically perceived as exclusive to his own group, then he might remain in harmony with a Kantian perspective if the maxims he accepts and would have as universal for all mankind discriminate on the basis of group affiliation

rather than individual qualities. At the same time such an individual would have to accept that a universal policy protective of the identity of groups rather than individuals could run counter to his personal interests if he found himself suddenly among members of a group other than his own. Here is the contradiction intrinsic within such approaches. If a universal law is protective of group identities it must of necessity restrict the rights of those who find themselves in an alien group and that new group (the set of individuals who find themselves outside of their own group) is without protection of any law in its interest. Therefore, if a law is truly universal, then it cannot be protective of one group any more than another just as it cannot be more protective of one individual more than any other.

A dilemma may arise when, by virtue of the universal nature of the law and the equal application of maxims, the individuality of some may be compromised. Special consideration for individuals with universally recognized special needs may seem to run counter to universal equality. Nonetheless, without such special considerations, children, who are a group with a definite identity (younger age) could not receive the special protections they need. This is unlike special considerations for groups identified on any other basis because children are a part of every group.

which exists in perpetuity. Without children there would be no continuation of any societal group. Women, as exclusive child bearers, may also be connected to this special group with some rights beyond what would be universally anticipated.

The comments from parents presented in the section on parent-school conflicts all have to do with the central theme of societal responsibility for the handicapped. Although policies at every level of government in the United States reflect an increasing acceptance of responsibility for civil inequity among the various minorities of our society including the handicapped, each group continues to struggle for what they feel is a fair approach to their particular circumstances.

The unique element of the situation posed by handicapped children is that they permeate every other group in society, be it minority or majority. Every group that includes members of childbearing age has the potential to have a handicapped child. Even senior citizens who are beyond childbearing age are potential grandparents, caretakers and familially responsible for the welfare of handicapped offspring.

What should be the duty of the community toward handicapped? How, in the name of fair and democratic government, should resources be divided and made available

to provide for handicapped children and thereby alleviate the source of conflict between parents and society.

Kant places primary responsibility for children in the hands of parents. He does not mention specifically any societal duties toward children beyond what is universal for all. Children are, for Kant, the "possessions" of their parents until they obtain their majority. Parents have duties toward children and children have duties toward parents, but society outside of the family bears no special responsibility toward children. Nonetheless, if society should act collectively on the basis of Kant's categorical imperative laws could be formulated to provide for the division of resources so that the special burdens borne by parents of the handicapped in terms of medical costs and educational needs could be alleviated. Such provisions of the law would only be acceptable from a Kantian perspective, if they were universal for all who qualify for them, that is, truly have need of them.

Herein lies, however, another source of conflict. Judgements would have to be made as to who deserves special consideration and who does not. Society would have to define qualifications for being handicapped. Clearly the resources of any society are not unlimited and some decisions would have to be made as to which children qualify for what services. A society that truly did not

have the resources to fairly meet the needs of its handicapped children would not be found in error, from a Kantian view, if the decision was made not to provide any special services to handicapped children. In that case, parents would be totally responsible to provide whatever a child needed beyond what was generally provided by society for all children.

#### Attitudes of Professional Educators

On pages 109 through 137 conflicts are discussed which arise because of the lack of regard some professionals express toward the parents of handicapped children. These problems can be generalized as stemming from a lack of fairness without prejudice toward others. Educators, like many professional, can be protective of their profession and the institutions they work in. They are concerned about the level of control they have in their work environment and often have difficulty managing any exception to what they are accustomed to. A child who demands more attention because of his slowness to learn or a child who is disruptive and threatens the order of the class can usually be dealt with by an experienced teacher as long as the

child can be viewed in the context of "normal" child. If, however, the teacher is offered an alternative diagnosis, even if that diagnosis is irrelevant to the educational concerns the teacher has for the child (as in the case of a physically handicapped child) then an effectual door is opened for the teacher to deal with the child as a "special" student. The regard for the parent which should be equal to the regard the teacher expects to receive from the parent is couched in the perspective of the parent as also "special" and perhaps not as capable as otherwise might be expected of providing "education" for the child. There is also the element of the education professional's rescue fantasy which may not only be manifest toward the child, but also toward the parent. The educator may want to rescue the parent from the burden of concern for the child's education. The parent may be viewed as frustrated, over anxious, and too much involved in the child's education. Many educators do not appreciate parental interference in their pupil's education.

Following the guidance of the categorical imperative teachers should ask themselves what they would do if they were the parent and the parent were the teacher.

## Euthanasia and the Handicapped Newborn

This section addresses issues of society's concern for its own identity as more or less tainted by the presence of undesirable elements. With medical technology offering convenient methods of eliminating unwanted pregnancies and unwanted infants because of the defects they present possibilities for the pursuit of eugenics are made more convenient than ever before. Infanticide through deliberate neglect and the abortion of "defective" fetuses represent measures that professionals and parents pursue in order to avoid the burdens of caring for children who are less perfect in appearance or capabilities than what is commonly found in society.

This situation is further aggravated by the inability of infants and fetuses to advocate in their own behalf. Their citizenship is more easily compromised because they have not formed the societal bonds which insure the commitment of society for their welfare. If they would be perceived by society as citizens with equal rights under the law, then they could expect fair and just treatment and the protection of the courts. The hope that a government ruled on the basis of the categorical imperative and offering infants and the unborn the same universal privileges as any other individual might enjoy must be

couched in the recognition that human nature tends to prompt the shunning of what is unlike perceived norms. To kill infants would be understood as murder and mothers like Carrie Buck, who was sterilized in order to avoid the suspected pollution of the genetic integrity of society, would not be subjected to such erroneous prejudices if true compassion for the welfare of all on a fair and equal basis were the norm in society.

### Suicide

The final review in this work discusses the area of childhood suicide and the rights under the law of children who attempt to commit suicide. Because children are, upon such action, considered to be emotionally disturbed they are necessarily included among those handicapped and qualifying for special educational services. The issue appears to be one of society's interest in the preservation of life versus the rights of individuals to privacy and self-determination. An intervening element in this debate is the specificity of laws to certain age groups based upon the relative ability of members of an age group to look after their own welfare. Certain laws are considered acceptable in application to one age group and not another.

Kant is quite specific in his declaration of the parental right to govern the child. However, no parent can completely shield a child from knowledge of societal promptings. As pointed out in the review on childhood suicide, the power of an open debate regarding the possibility of a right to self-termination could have a devastating impact upon some less stable youth. Parents may best apply their energies to the development of understanding and communicative bonds with their children if they are concerned about their child's vulnerability to the influence of debates in society.

Kant's expressed concept of parental responsibility would accept standards in society which are particular to age and the level of responsibility manifest by that age. Children are, for Kant, parental possessions and, as such, also a parental responsibility.

## CHAPTER 8

### EPILOGUE

This dissertation has reviewed literature relative to the conflicts between families and society regarding children who require special educational services. Specific cases and areas of special concern were then presented. These cases offered details of the dilemmas that parents, schools, government agencies, courts and other bodies representing society's interests face. A philosophical perspective based upon some of the writings of Immanuel Kant was then provided. With this basic framework for the formulation of possible working principles to guide the successful working out of the conflicts which arise between families and society the situations and concerns presented previously were examined with an eye to amelioration through a Kantian approach. This is not to suggest that Kant had something to offer that would be applicable in every case, rather that the fundamental principles Kant espoused, if absorbed in the thinking of both parties to the conflicts discussed, could offer a vehicle for the successful resolution of the conflicts.

Problematic to these situations is the reality of human judgement and prejudice which is formed very early in life. Because the conflicts discussed are intrinsically grounded in emotions, compassion and attitudes, offering fundamental philosophical principles as a means of relieving conflicts is difficult at best. One cannot simply declare that if both sides would have as guiding principles of their lives Kant's categorical imperative all would be well. Not only will each individual interpret the application of that principle in his own way and place emphasis on the importance of different values, but such principles, to have significant effect upon judgements and attitudes, must be a part of the upbringing of individuals from their earliest years. Indeed, it is unreasonable to expect that such deeply rooted attitudes as the personal prejudices and unconscious feelings toward the handicapped would be easily affected by the introduction of a philosophical perspective such as Kant's.

Individuals cannot easily assess what their true response to certain situations would be without being placed in those situations. No matter how benevolent, or patient, or fair people may view themselves to be, when the moment of truth arrives, when the handicapped newborn comes forth in the delivery room, or when a child suffers irreversible central nervous system damage, just how a

parent will react, no one can predict. Similarly, the roots of a professional's attitude and expectations run far deeper than post secondary learning. A case in point: In 1978 a nurse who had an exceptional record of service to handicapped children gave birth to a child with spina bifida. She insisted that the child not be treated, but allowed to die by withholding any lifesaving medical intervention. In an interview it was discovered that her brother had died of complications secondary to spina bifida at the age of 20. Caring for him during his life had been a draining experience for their mother and there were many unresolved feelings about the attentions this sibling had received, the effect of his handicap, the odor resulting from his incontinence and the nurse's perception of an impaired adolescent social life because of the presence of the handicapped brother.

Attitudes about the handicapped, parenting, appropriate professional roles, the duties of government and educational systems, all reflect societal norms as well as individual feelings. These norms and feelings reflect the inseparable history of families and of society in general. The evolution of American perspectives on education, family, and government has not been without significant influence from eighteenth century philosophy. The writings of Locke, Hobbs, Rousseau, Montesquieu and

Kant reflect perspectives that are the product of late eighteenth century Romanticism and have left an indelible mark on modern society. Integrating of Kantian values into American thought could renew the strength of a rational sense of fairness. This interaction might provide approach to the conflicts that arise between families and the agencies of society, based on fundamental principles akin to those upon which American government was founded.

Such principles as may follow from the categorical imperative can hardly become a significant part of a family's approach to conflicts without the general understanding of this approach to human relations among the institutions of society. A family with a clear model of the parental and societal roles in the education and rearing of their children as elucidated by Kant cannot truly expect to avoid conflict. Conflicts are inevitable. However, with an instrument for thinking through and rationally approaching conflicts, solutions can be brought about. Such a vehicle is Kant's approach to human relations as described in the Fundamental Metaphysics of Morals. Not a tool to be taken from the shelf and applied to the "fixing" of conflicts, but rather a way of thinking which, when part of the warp and woof of individual, familial, and societal philosophy can offer an understanding that transcends the misjudgment that leads to

conflict between families and society and through which, when the unavoidable conflicts do arise, rational solutions can be found which are available to all rational parties.

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APPROVAL SHEET

The dissertation submitted by Stephen B. Parrish has been read and approved by the following committee:

Dr. Walter Krolikowski, Director  
Professor, Education, Loyola

Dr. Marcel Fredericks  
Professor, Sociology, Loyola

Dr. Gerald Gutek  
Professor, Education, Loyola

Dr. Steven Miller  
Professor, Education, Loyola

The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the Committee with reference to the content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

12 March 90  
Date

W P Krol (Cons K)  
Director's Signature