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THE DEATH AND BURIAL OF THE PERSON
WITH
MENTAL RETARDATION

by

Father Michael J. Gilsenan, ss.cc

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This research paper has been
approved for the Graduate Committee
of the Cardinal Stritch College by

S. Gabrielle Kowalski
(Advisor)

Date May, 1979

DEDICATION

This research paper is dedicated to Brian Dempsey, Dottie Wiggins, Trudy Terusa, Dee Dee Hatzidakis and the many others, who have reached their final stage of growth, have made their final decision in death with God, and whom I had the unique privilege of working with, knowing, loving, serving, and of being loved by. To their parents who bore them in great joy and sorrow and are loved and honored by them for all eternity.

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CHAPTER I

INTRODUCTION

Statement of the Question

> The phone rang with its usual urgency. A subdued voice spoke--: "Dottie just died." "I'll be right there." It was February 23rd, 1976. Seven months later it rang again. This time it was early morning--through tears and feelings of deep grief, a young mother haltingly spoke, "Brian, he--is gone. Can you come?" "I'll be right there." A year later another phone rang--this time a mother answered. "This is ____ at Pacific State, your daughter Trudy is having difficulty breathing. The doctor is working with her; can you come?" "I'll be right there." Forty minutes later an elevator door opened and mother and family stepped into the corridor and moved quickly to the familiar bedside--five minutes too late.
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> Across America, across the world, across time, similar calls, similar scenes have, are and will take place. Death has come like a "thief in the night"[1] and lives are changed, dreams shattered, voids and vacuums created, dams of grief broken and questions of why? what? how? what now? burst forth on the torrid silence.

What have all these in common? Death: the vital signs of life have ceased and the medical personnel have declared with certainty that the person is dead and an uncertainty begins. Mental Retardation: those who have died lived human lives which were hampered in their development by mental retardation. They lived short lives of

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[1] Thes. 5:2 (NAB).

twelve, five and twelve years respectively and were the bearers of great joy and great suffering.

> For birth hath in itself the germ of death
> But death hath in itself the germ of birth
> It is the falling acorn birds the tree
> The fern--plants moulder when the ferns arise
> For there is nothing lives but something dies
> And there is nothing dies but something lives
> Till the skies be fugitives.
> Till time and hidden root of change, updries
> Are Birth and Death unseparable on Earth
> For they are twain yet one, Death is Birth.
>
> "Ode to the Setting Sun"[1]
> Francis Thompson

For the parents, the funeral and burial was a time of grief and mourning. The funeral itself prompted serious questions. Shouldn't the funeral reflect the life of the person who has died and be conducted according to the principles of normalization? What is a normal funeral service for a Christian? The traditional Roman Catholic funeral service attempts to adequately synthesize the sorrow, the joy, the present reality, the past life of the individual and the feelings and emotions of the parents and friends who attend. Or does it? What would a Catholic priest, a friend of the family, a friend of the deceased do, say? What does the "death and burial of a person with mental retardation" really mean to the parents, friends and to the reader?

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[1] Francis Thompson, "Ode to the Setting Sun," in Selected Poems of Francis Thompson (New York: Thomas Nelson and Sons, 1938), p. 238.

Statement of the Intention

This paper will attempt to review the literature regarding these problems. It will attempt to present some pastoral guidelines for the clergy and all who work with people with mental retardation. It will attempt to provide some support for the parents who have lived the joy and the sorrow and are ably described by Ginott when he says:

> Life is so daily. Parenthood is an endless series of small events, periodic conflicts and sudden crises, which call for a response. The response is not without consequence: It affects personality for better or worse.[1]

This paper will not deal with the process of death itself, nor with the understanding of feelings, emotions, and reactions toward death in general of the person with mental retardation. It will not deal with the personal reactions of persons with mental retardation toward their own deaths.

It will attempt to review the literature regarding the parents' feelings and reactions to the birth of the child who is diagnosed as having some degree of mental retardation, especially to a moderate, severe or profound degree. It will review the literature regarding the chronic sorrow and mourning of the parents following the birth of the child with mental retardation. Literature regarding

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[1] Haim Ginott, Between Parent and Teenager (Toronto, Ontario: Macmillan Publishing Co., 1969), p. 243.

pre-death and the parents' reactions to terminal illness in their child, as well as the treatment and care of the severely and profoundly handicapped child during this time, will be reviewed. The author will attempt to describe the secular, Jewish and Christian understandings of death. The funeral rite will be reviewed, especially as it relates to the Judeo-Christian tradition. From this review of the literature conclusions will be drawn to assist the parents, the clergy and the reader at the moment of the death and burial of the person with mental retardation.

Definition of Terms

Terms used in this study and needing clarification follow.

Death: "Death has occurred when every spontaneous vital function has ceased permanently."[1]

For the purpose of this paper, death will be understood to mean that medical personnel have declared the person to be dead and have signed the death certificate. The cause of death will not be investigated.

Mental Retardation: "Mental retardation refers to significantly subaverage general intellectual functioning

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[1] Jon Voight, "The Criteria of Death, Particularly in Relation to Transplantation Surgery," World Medical Journal 14 (September-October 1967):144.

existing concurrently with deficits in adaptive behavior and manifested during the developmental period."[1]

There are four levels or degrees of mental retardation: mild (67-52 IQ); moderate (51-36 IQ); severe (35-20 IQ); and profound (19 IQ and below). For the purpose of this paper the person with retardation will be understood as having a moderate, severe or profound degree of mental retardation.

There are specific syndromes which generally result in mental retardation and definitions of two of these follow:

> Down's Syndrome: A syndrome in which the majority of affected individuals are trisomic for chromosome number 21. Clinical manifestations include epicanthal folds, oblique palpebral fissures, broad bridge of the nose, protruding tongue, open mouth, square shaped ears, muscular hypotonia, often congenital heart disease and varying degrees of mental retardation.[2]

The term mongolism or mongoloid was used in the past to refer to what is now referred to as Down's syndrome.

> Hurlers Syndrome: A syndrome of mucolysaccride metabolism associated with characteristic facial appearance including broad ridge of the nose, open mouth with protruding large tongue, thickened lips, corneal clouding.

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[1] Hubert J. Grossman, M.D., ed., Manual on Terminology and Classification in Mental Retardation, 1977 Revision (Washington, D.C.: American Association on Mental Deficiency, 1977), p. 11.

[2] Ibid., p. 133.

The facial features are coarse. Herpatomegaly and hypertuchosis are present. Mental retardation is present. Transmitted as autosomal recessive.[1]

Summary

What does the death and burial of the person with mental retardation really mean to parents, friends, and to the reader? This paper is an attempt to answer this question by reviewing the literature regarding the emotions, feelings and reactions of the parents to the death of the person with mental retardation. By reviewing the literature regarding the funeral rite as it reflects the life and death of the person with mental retardation, plus the grief, sorrow and possibly joy experienced by the parents. Conclusions will be drawn to assist the parents, friends, and the reader in the milieu occasioned by the death and burial of the person with mental retardation. Terms relevant to the study and limitations on its scope were defined.

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[1] Ibid., p. 142.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

A review of the literature shows only one reference to the actual death and burial of the person with mental retardation. This is made by Nichols and Nichols[1] when they describe in detail the funeral and burial of a one year old baby who had Down's syndrome. They also describe the feelings and reactions of the parents and their participation in the funeralization process.

However much has been written on the birth of the person with mental retardation and the effects on the parents. Is there a connection? The literature seems to suggest that there is. The literature seems to suggest that reactions to the birth, such as chronic sorrow, mourning, death wishes, are similar to those experienced at the death of a loved one.

Thus Funderburk states when writing about the counseling center at the University of California at Los Angeles:

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[1] Roy Nichols and Jane Nichols, "Funerals: A Time for Grief and Growth," in Death: The Final Stage of Growth, ed. Elisabeth Kubler-Ross (New Jersey: Prentice-Hall, Inc., 1975), pp. 87-96.

In addition to biomedical facts about Down's syndrome and prevention in future pregnancies by amniocentesis, the parents are assisted with coping mechanisms. They are instructed about the basic psychological reactions to human trauma quite similar to those described by Kubler-Ross for the terminally ill patient.[1]

The basic psychological reactions to human trauma or coping mechanisms are described by Kubler-Ross as denial and isolation, anger, bargaining, depression, acceptance.[2]

She describes the first stage, denial and isolation as: "Denial functions as a buffer after unexpected shocking news, allows the patient to collect himself and with time, mobilize other, less radical defenses."[3] The second stage is described as: "Anger . . . when the first stage of denial cannot be maintained any longer, it is replaced by feelings of anger, rage, envy, and resentment. The logical next question becomes "Why me?".[4] The next stage is bargaining: If we have been unable to face the sad facts in the first period and have been angry at people and God in the second phase, maybe we can succeed in entering into some sort of an agreement which may postpone the inevitable happening."[5] Depression is described:

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[1] Steve Funderburk, Karen Richardson, Joan Johnson, "The Adaptation of Parents: Postpartum Crisis Counseling," Pediatrics 63 (September 1977):383.

[2] Elisabeth Kubler-Ross, On Death and Dying (New York: Macmillan Publishing Co., 1969; Macmillan Paperback edition 1974), pp. 38-112.

[3] Ibid., pp. 39-40.

[4] Ibid., p. 50.

[5] Ibid., p. 82.

> When the terminally ill patient can no longer deny his illness, when he is forced to undergo more surgery or hospitalization, when he begins to have more symptoms or become weaker and thinner, he cannot smile it off anymore. His numbness or stoicism, his anger and rage will soon be replaced with a sense of great loss.[1]

The final stage is one of acceptance: "If the patient had enough time and has been given some help in working through the previously described stages, he will reach a stage during which he is neither depressed nor angry about his fate."[2]

At the counseling center mentioned above do they instruct parents who have given birth to a child with mental retardation on the phases of grief experienced by a person after the death of a loved one as described by Ogg?[3] It is not stated in the article by Funderburk,[4] yet these phases are similar to those stages of coping with death previously described by Kubler-Ross.[5] Ogg proposes

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[1] Ibid., p. 84.

[2] Ibid., p. 112.

[3] Elisabeth Ogg, A Death in the Family (New York: Public Affairs Pamphlets, 1976), pp. 2-8.

[4] Funderburk, et al., "The Adaptation of Parents: Post-Partum Crisis Counseling," p. 383.

[5] Kubler-Ross, On Death and Dying, pp. 38-112.

that there are distinct phases in normal bereavement, which last longer for some people than for others, and which may overlap. They are "shock and numbness . . . disbelief and illusions . . . a time of inner conflict . . . the burden of guilt . . . feelings of anger . . . aloneness . . . expressing grief . . . delayed, inhibited and chronic grief are three kinds of extreme reactions that seriously hamper working through grief to a stage of acceptance and reintegration.."[1]

Pearl Buck seems to experience one of these reactions or goes through one of the coping stages or phases of grief. She says:

> The first cry from my heart, when I knew she would never be anything but a child, was the age-old cry that we all make before inevitable sorrow: "Why must this happen to me?" To this there could be no answer and there was none.[2]

This paper will review descriptions of the experiences and reactions of the parents following the birth of their child who has profound, severe or moderate retardation, in order to better understand their feelings and reactions at the death and burial. For the same purpose it will discuss the parents' feelings and reactions to terminal

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[1] Ogg, A Death in the Family, pp. 2-7.

[2] Pearl Buck, The Child Who Never Grew (New York: John Day Co., 1950), p. 6.

illness or the pre-death of their child. The secular, and Judeo-Christian viewpoints on death itself and the funeral rite will be reviewed. The conclusion will provide guidelines to assist the parents and the reader in dealing with the death and burial of a person with mental retardation.

Birth of a Child with Profound, Severe or Moderate Mental Retardation and the Effects on the Parents

Birth is, in a way, a miraculous event, for each person born has limitless potentials and possiblities. Each individual has the power to love, to create, to share, to discover new alternatives and bring new and fresh hope for humanity. Birth, for most families, is a time for rejoicing, for pride, for gathering together loved ones and sharing with them in the celebration of renewal of life.

For other families birth may not be as joyful an occasion. On the contrary, it may be a time for tears, confusion, fear and despair. A new lifestyle, filled with unique and mysterious problems, may be demanded of all involved.

Many such examples are discussed in the literature by parents themselves and by professionals. One mother wrote a manual to help other mothers. In the introduction she describes her present feelings, and later states:

> This attitude was not the same, the first nine months of our little Mark's life. I was not prepared for it, no one ever is. Imagine being told your baby

> is retarded. You never think this could happen to you. I sat there stunned before I could ask inevitable and endless questions. Some the doctors could answer; some the clergymen could answer; but none of these professional people had a retarded (or handicapped) child. I'd never seen a Mongoloid, so I didn't know how bad they were. I needed and wanted another mother of a Mongoloid [Down's syndrome] child to tell me how she accepted her child, how he would fit into the family, what he was like at the two a.m. feeding. I wanted to ask hundreds of questions a doctor could not tell me.[1]

Robinson gives a step by step account of the parents' reactions after the doctor informs them: "Eddie is the victim of one of nature's accidents. I'm afraid his brain will never develop. He has all the signs of feeblemindness."[2]

She lists three stages which the parents go through. Stage one is a frantic searching for proof that the child is not sub-normal. Stage two is a crusade to prove the specialists wrong. Stage three takes place only when both parents accept their child as sub-normal and arrange their lives accordingly.

> Stage one consists of (1) repudiation of the family physician, (2) correspondence with authorities in the field of abnormal psychology and (3) visits to psychiatrists and specialists all over the land. This period lasts as long as family finances allow.[3]

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[1] Helen A. McClinton, <u>Mothers Mutual Manual</u> (Colorado Springs, Colorado: El Paso County Association for Retarded Children, 1967), p. 2.

[2] Roberta Robinson, "Don't Speak to Us of Living Deaths" in Robert L. Noland, ed. <u>Counseling Parents of the Mentally Retarded</u> (Springfield, Ill.: Charles Thomas, 1970), pp. 5-18.

[3] Ibid., p. 8.

> During stage two, when there is a crusade to prove the specialists wrong, the husband senses a gradual change in his wife. She loses all interest in sex, refuses to mix in society, neglects her ordinary work and devotes every waking hour to frenzied training of her child. If this stage persists too long, it may lead to the mother's complete insanity.
>
> Stage three takes place only when both parents accept their child as sub-normal and arrange their lives accordingly. . . . the child is at home, the mother often devotes her days to the child's care. Sometimes a semblance of home life remains, but the parents often through fear, or because of knowledge obtained through the genetic counselor, resolve never again to have children. The most stable people place their child in an environment specially created to care for him. These parents have two alternatives. First, they can keep the child at home as a member of the family, have other children and build as nearly normal a home-life as possible. Or they can put him or her in an institution, family care home, convalescent home, board and care home, have other children, and build a happy life without him or her.[1]

Other writers describe stages similar to those mentioned above. Murray[2] lists six stages, or problem areas, which are shared by many families of retarded children. These will vary in importance, impact or degree, according to the individual family situation and the particular child involved. They are: (1) acceptance of the fact that the child is retarded; (2) financial difficulties; (3) emotional build-up which is brought on by the difficulty of sharing the news and information about their child with others; (4) theological conflicts which arise in the minds of parents when faced with a heart-rending situation within their

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[1] Ibid.

[2] Dorothy G. Murray, "Needs of Parents of Mentally Retarded Children," American Journal of Mental Deficiency 63 (May 1959):1078-1088.

personal lives such as the birth of a child with mental retardation; (5) search for a solution to the matter of satisfactory life time care for the child with retardation; (6) coping at one time or another with often inept, inaccurate and ill-timed advice.

Boyd talks about three stages which a parent goes through. He first details his reaction to the news about the birth of his child:

> "I am afraid that your baby is not a normal child. I think she is a mongoloid." The earth seemed to rise up around me and the heavens seemed to crash upon my head. A mongoloid child. What was a mongoloid child? I had heard the name, but my recollection was vague and tinged with horror. A thousand thoughts raced across my brain with kaleidoscopic rapidity. Was this the result of heredity? Was there no hope at all? Why did this have to happen to me? Why had God singled me out from all other men, to place this burden upon me. Why? Why? Why?[1]

He continues by describing the first stage as an entirely subjective one, in which the person is totally concerned about the self. In stage two, the person thinks less of the self and more of the child. Stage three follows; the parents begin to think more of what they can do for other parents and their mentally retarded children and less about what others can do for them.

The stages through which the parents go, as well as their problems and needs were recognized by the President's Panel on Mental Retardation.

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[1] Dan Boyd, "The Three Stages in the Growth of a Parent of a Mentally Retarded Child," American Journal of Mental Deficiency 55 (April 1951):608.

> Acceptance by the parents of the true nature of their childs' handicap is essential if they are to be effective in helping him or her . . . . The physician and the other professional people dealing with the family do not always appreciate the severe crisis through which its members pass during the weeks or months following the revelation of their child's affliction.[1]

The word "acceptance", as found in a review of the literature, is frequently used in reference to the parents' feelings toward their child who has mental retardation. However, parental rejection is also discussed, especially by professionals. It is important to understand this phenomenon when discussing the reactions of the parents following the birth of their child with mental retardation. Gallagher defines rejection as "the persistent and unrelieved holding of unrealistic negative values of the child, to the extent that the whole behavior of the parent towards the child is colored unrealistically by this negative tone."[2]

In his discussion, he presents four general areas where parental rejection can be expressed: (1) strong, underexpectations of achievement, where the child is considered so useless that he/she is considered incapable of doing anything; (2) goals are set so high for the child that

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[1] President's Panel on Mental Retardation, A Proposed Program for National Action to Combat Mental Retardation (Washington, D.C.: Government Printing Office, 1963), p. 89.

[2] James J. Gallagher, "Rejecting Parents?" Exceptional Children 22 (April 1956):273-276.

when s/he does not achieve, this is used to justify the negative feelings; (3) escape, which can be either abandoning the child or placing the child at a great distance from the parent; (4) reaction formation, where the negative feelings that the parents have toward the child are so unacceptable to their own total picture of themselves as kind, warm, loving individuals that they deny their feelings and present to others the exact opposite feelings.

Other authors suggest variables which affect the acceptance or rejection by the parents of their child with retardation. One of these is parental position on the socioeconomic ladder.

> The potency of child-care problems associated with mental retardation is related to socioeconomic status in affecting family relationships. As long as high socioeconomic status parents are uncertain about potential intellectual development of the retarded child, their family relationships may be profoundly affected. However, as soon as the child is diagnosed as severely retarded, the discrepancy between his other familial, social, and economic labels and his intellectual label is sufficiently great to produce great emotional impact . . . . For low economic level families however, since the label itself is presumably not the primary crisis-evoking factor, child-care problems themselves provide the basis for family tension.[1]

Other factors may be the age and sex of both child and parents, etiology as perceived by parents, social and religious background, and the interaction between intrafamily and extrafamily relationships. Another very

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[1] Bernard Farber, Mental Retardation, Its Social Context and Social Consequences (New York: Houghton Mifflin Co., 1968), pp. 38-39.

important factor is the understanding by the parents of what a child means. Ryckman and Henderson mention six areas concerning the meaning of children with retardation to their parents:

> (1) The parent views the child as a physical and psychological extension of himself. (2) The child is means of vicarious staisfaction to the parents. (3) The parents can transcend death through their child, i.e. derive some measure of immortality. (4) A fourth area of meaning of children for parents is the concept of a personalized love object. (5) Another area is the parental feeling of worth in meeting the dependency needs of the child. (6) The negative feelings the parents may have about the limitations and demands of child rearing.[1]

The concept of guilt seems, according to a review of the literature, to play a part in the parental acceptance or rejection of the child. Zuk studied this area.

> To what extent can the better acceptance of the Catholic mothers be attributed? In the writer's opinion, it is due to the explicit absolution from personal guilt offered by religious belief. Catholic doctrine provides considerable emotional support for mothers by its insistence that every child, normal or defective, is a special gift of God bestowed on parents. Indeed, the birth of a retarded child may be perceived by the devout Catholic mother as a unique test of her religious faith. It is the writer's impression that the Catholic is much less subject to the kind of searching self-examination that

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[1] David B. Ryckman and Robert A. Henderson, "The Meaning of a Retarded Child for His Parents: A Focus for Counselors," <u>Mental Retardation</u> 3 (August 1965):4-5.

> often results in the development of strong guilt feelings. She is not likely to ask herself, "What have I done to have such a child?" She is more willing to accept the fact that the birth of the child was the result of a decision made by high spiritual authority. It is not hard to see how acceptance of this decision is a major step along the path to acceptance of the child.[1]

In the conclusion of his work, Zuk also states:

> It should be appreciated that parents of a retarded child are often subject to extreme conflict; they are caught between strong feelings of love and hate toward the affected offspring. These contradictory feelings tend to result in the arousal of a guilt reaction. In the writer's experience, few parents openly admit to guilt. It is more likely to be seen projectively, that is, in such reactions as a rejection or fostering over-dependency, or putting too much pressure on the child to perform.[2]

The literature indicated that parents experience, following the birth of a child with mental retardation, the basic psychological reactions to human trauma experienced by the terminally ill patient. These were denial and isolation, anger, bargaining, depression and acceptance. It also indicated that parents go through different stages at the birth of a child with mental retardation. These were, according to one author,[3] the frantic searching

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[1] G. H. Zuk, "The Religious Factor and the Role of Guilt in Parental Acceptance of the Retarded Child," American Journal of Mental Deficiency 64 (July 1959):145.

[2] Ibid., p. 146.

[3] Robinson, "Don't Speak to Us of Living Deaths," pp. 5-18.

for proof that the child is not handicapped, the crusade to prove the diagnosis wrong, and the final acceptance. Another author [1] mentions similar stages: acceptance of the fact; using financial resources; emotional build-up; theological conflicts; the search for a solution; and the coping period. A third author[2] describes three stages: the involvement with the self; the involvement with the child; and finally the involvement with others.

The literature considers the concept of acceptance and its opposite, rejection, in relationship to the feelings about the child with mental retardation. Factors such as the parents' position on the socioeconomic ladder, the severity of the retardation and child-care problems are given as variables which affect the acceptance or rejection by the parents of the child with mental retardation. Other factors such as age, sex, etiology, social and religious background were also considered. What a child means and how the parents see and understand their child with mental retardation was considered as being a very important factor in acceptance. The part that guilt plays in acceptance was

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[1] Murray, "Needs of Parents of Mentally Retarded Children," pp. 1078-1088.

[2] Boyd, "The Three Stages in the Growth of a Parent of a Mentally Retarded Child," p. 608.

studied by one author,[1] who suggested that Catholic mothers were more accepting of their child with mental retardation than other mothers.

The literature advances three major reactions of the parents to the birth of their child with retardation: mourning; chronic sorrow and death wishes. These will be considered more directly in the following section of this paper. The factors that shape the family's trauma, or that lead to the family's adaptive responses will be discussed.

Mourning, Chronic Sorrow and Death Wishes: The Birth of the Child with Mental Retardation

Mental retardation in a new born child is regarded by many parents as a personal and family tragedy and whatever one may do or say the tragedy remains. What do these parents really feel? Solnit and Stark propose that parents experience a mourning reaction.[2] They believe that the birth of a child with mental retardation is a severe narcissistic blow similar to the loss suffered through the death of a loved one, leaving the parents in a state of acute grief. They hypothesize that the mother expects to have a normal child and builds up a

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[1] Zuk, "The Religious Factor and the Role of Guilt in Parental Acceptance of the Retarded Child," p. 145.

[2] Albert J. Solnit, Mary H. Stark, "Mourning and the Birth of a Defective Child," in <u>Psychoanalytic Study of the Child</u>, Vol. 16 (New York: International Universities Press Inc., 1961), pp. 523-537.

fantasy image of him or her. The birth of the defective child means the loss of the normal child.

> In the mother's mourning reaction to the loss of the healthy child, her wishes for, and expectations of, the desired child are crushed by the birth of the defective child. Her anxious fears of having a damaged child are realized. These disappointed, highly charged longings for the normal child may be recalled, intensely felt, and gradually discharged in order to reduce the impact of the loss of the expected loved child. This process can liberate the mother's feelings and interests for a more realistic adaptation. The mourning process makes it possible to progress from the initial phase of numbness and disbelief; to the dawning awareness of the disappointment and feeling of loss with accompanying affective and physical symptoms; to the last phase of the grief reaction in which intense re-experiencing of the memories and expectations gradually reduce the excessive desire or wish for the idealized child. In childbearing, the simultaneous loss of one child and adaptation to the deviant or defective child makes a demand that is very likely to be overwhelming. There is no time for working through the loss of the desired child, before there is the demand to invest the new and handicapped child as a love object.[1]

Olshansky argues against this hypothesis for four reasons. (1) The death of a dream child is not equivalent to the death of a real child. (2) Insufficient account is taken of the fact that, for many parents, identification of mental deficiency does not take place at birth. (3) Those parents who passed the period of mourning should be free of sorrow and should be able to attend the needs of their child. (4) It places the problem within the psyche and appears to define the parents as neurotic.[2]

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[1] Ibid., p. 526.

[2] Simon Olshansky, "Parent Responses to a Mentally Defective Child," Mental Retardation 4 (August 1966): 21-23.

Olshansky proposes that parents who have a mentally defective child suffer chronic sorrow throughout their lives.[1] This sorrow is particular to the family, depending upon the circumstances, background, the condition of their child and it varies in intensity from time to time. It is not to be viewed as a neurotic manifestation, but rather as a natural and understandable response to a tragic fact. He gives as a justification for the chronic sorrow, the reality faced by the parent of a child with severe mental retardation.

> When the parent is asked to accept mental deficiency, it is not clear just what he is being asked to do. The great stress professional workers tend to place on acceptance may suggest to the parent that he is expected to perceive his child from the point of view of the professional helper. This expectation may make him both resentful and resistant.[2]

Olshansky feels the sorrow is chronic in that it lasts as long as the child lives.

> The woes, the trials, the moments of despair will continue until either their own deaths or the child's death. Concern about what will happen to his child after he is dead may be a realistic concern for a parent, or it may be associated with death wishes either for himself or for his child. Release from his chronic sorrow may be obtainable only through death.[3]

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[1] Simon Olshansky, "Chronic Sorrow: A Response to Having a Mentally Defective Child," Social Casework 43 (April 1962):190-193.

[2] Ibid., p. 191.

[3] Ibid., p. 192.

Death wishes are mentioned among the reactions and feelings experienced by many parents toward their child with retardation according to Roos.

> Resentment and hostility generated by repeated frustrations may be expressed in death wishes toward the child and feelings of rejection. Typically such feelings arouse considerable guilt in the parent, who then tries to atone for his hostility by developing overprotective and overindulgent attitudes toward the child.[1]

The death wish of the parents toward their child with mental retardation is often expressed in the counseling session. Mandelbaum describes the parents' feelings, reactions and participation in the group counseling process:

> The parents praise each other's children and during the expression of such positive feelings they slowly venture to speak of their anger and fright at the persistent intrusion of intense death wishes. Many say in effect, "Having a retarded child is like having a death in the family, only worse; at least you can get over a death, but this is never behind you. You have to live with this, for the rest of your life."[2]

This same feeling was expressed by a famous parent who wrote a book about her child with mental retardation.

> All the brightness of life is gone, all the pride gone, there is an actual sense of one's life being cut off in the child. The stream of the generations is stopped. Death would be far easier to bear, for death is final. What was, is no more. How often did I cry out

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[1] Philip Roos, "Psychological Counseling with Parents of Retarded Children," Mental Retardation 1 (December 1963): 345.

[2] Arthur Mandelbaum, "The Group Process in Helping Parents of Retarded Children," in Children Vol. 14 (Washington, D.C.: Dept. of Health, Education and Welfare, Children's Bureau, 1966):227-232.

> in my heart, that it would be better if my child died. If that shocks you, who have not known, it will not shock those who do know. I would have welcomed death for my child and would still welcome it, for then she would be finally safe.[1]

Perske in alerting pastors to some of the critical situations to expect in the lives of the parents of people with mental retardation mentions:

> There will nearly always be death wishes in the families of the mentally retarded. This shouldn't be alarming since aggressive fantasies are present in even the most warm and wholesome relationships at certain times. Often these death wishes are denied and pushed back. They can cause real problems in the relationship with the mentally retarded person. A skilled pastor may be very helpful in the struggle to recognize them, understand and deal with them.[2]

This paper, in this section, has reviewed the literature with regard to the effects of the birth of a child with mental retardation on the parents. It was proposed that the birth of a child with mental retardation was a severe narcissistic blow, similar to loss suffered through the death of a loved one, leaving the parents in a state of acute grief. Since the mother expects a perfect child, the birth of the defective child means the loss of the normal child. The mother goes through a mourning process for the perfect child prior to the

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[1] Buck, The Child Who Never Grew, p. 27.

[2] Robert Perske, "The Pastoral Care and Counseling of Families of the Mentally Retarded," Pastoral Psychology 19 (November 1968):27.

acceptance of the child with retardation. On the other hand, it was proposed that the parents suffer chronic sorrow throughout their lives. This chronic sorrow varies in intensity according to circumstances and time. A number of authors suggested that the reaction to, or the concern for, the child with mental retardation was often expressed in death wishes. While these aroused guilt feelings in the parents, they should not be seen as alarming or indications of neurosis. Often they were denied and pushed back. The next section of this paper will review the theological crisis, or the God question, as it affects the parents following the birth of their child with mental retardation. This review will attempt to assist the parents and the reader toward a better understanding of the possible theological crisis, or God question, experienced by the parents at the death and burial of the person with mental retardation.

Theological Crisis Experienced by the Parents At the Birth of a Child with Mental Retardation

One often hears the expression, taken from the Bible or elsewhere, that life is a gift from God. This is found in the scripture quotation, "God created man in His image; in the Divine image He created him; male and female He created them."[1] Thus for a person with a

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[1] Gn 1:27 (NAB).

religious background the birth of a child would have theological implications. A review of the literature indicates that this is so especially at the birth of a child with mental retardation. One author, referred to earlier, mentions as the fourth problem experienced by the parents, the theological conflicts which arise in the minds of the parents when faced with such a heartrending situation within their personal lives. She explains that any condition of life which destroys or permanently damages one's concept of a loving and merciful God, presents a serious problem. She states:

> But to suddenly face the fact that their child is a mental cripple, and will remain so throughout life, well--this simply places them outside the providence of God's mercy and justice, or so they often feel--if they can still believe that there is a God.[1]

A review of the literature with regard to religion, parents, and mental retardation was compiled by Stubblefield, who concluded that there are two definite patterns of relationship between religion and parental acceptance.[2] (1) The birth of a child with mental retardation precipitates a theological crisis for many parents. (2) Not only does

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[1] Murray, "Needs of Parents of Mentally Retarded Children," p. 1086.

[2] Harold W. Stubblefield, "Religion, Parents and Mental Retardation," <u>Mental Retardation</u> 3 (August 1965): 8-11.

the birth of a child with mental retardation affect religious faith, but religious faith also affects the parents' response to this event.

A number of areas were seen to be involved in the theological crisis according to the author. One was the belief that the condition of retardation was the punishment of God, which then involves the problems of sin, guilt, and forgiveness. This belief represents man's persistent need to affix responsibility and to believe that God visits the sins of the fathers upon their sons. Another area was the positive effects the theological crisis could have. The author reported on a survey of two hundred and twenty clergymen:

> Forty-one percent had observed that a retarded child stimulated greater faith in the parents known to them, while twenty-eight percent had observed families who were brought closer to the church as a result of this experience.[1]

The second pattern, the birth affecting the religious faith, and the religious faith affecting the parents' response, has three religious factors as formative influences.

> The religious affiliation of the parents . . . . the religious interpretation of the cause of illness. . . . the religious teaching regarding the expression of feeling. Every religion and culture structures acceptable patterns for the expression of emotions and reactions to such crucial events as illness and death.

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[1] Ibid., p. 9.

Moral values are even attached to the kinds or intensity of emotions permitted to be expressed.[1]

Perske sums up the theological crisis when he says:

> Religious attitudes and beliefs often undergo radical change. In many instances, those who were not active in church will become active. Others who were extremely active become less active. They may even drop out or change church affiliation. Mental retardation comes as such a blow to most persons that their theological beliefs cannot help being shaken and reconstructed on another level.[2]

A positive theological crisis can result in a stage of development similar to the third stage in the growth of a parent of a child who has mental retardation, as described by Boyd.

> And as we experience the rewards that can come when we merge the problem of our child into the problem of all mentally retarded children, we shall realize the promise: "Give and it shall be given unto you; good measure, pressed down and shaken together and running over." And then we shall be able to look into our children's eyes and see them as they really are--God's children--and be thankful. "And God created man in His own image: in God's image created He him. And God saw everything that He had made and behold, it was good." 3

The birth of a child with mental retardation caused a theological crisis in the personal lives of the parents according to all the authors reviewed. It also, according

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[1] Ibid., pp. 9-10.

[2] Perske, "The Pastoral Care and Counseling of Families of the Mentally Retarded," p. 28.

[3] Boyd, 'The Three Stages in the Growth of a Parent of a Mentally Retarded Child," p. 611.

to some authors, affected the parents' faith positively or negatively. Conversely the religious faith also affected the parents' response to the birth and life of the child with mental retardation. This religious faith was described as having three religious factors as formative influences: religious affiliation of the parents, religious interpretation of the cause of illness and the religious teaching regarding the expression of feelings. One author, a parent of a child with mental retardation, equated the positive theological crisis effected by the birth of a child with mental retardation and the third stage of growth, the involvement of the parent of the child with mental retardation with other parents.[1]

The birth of a child with mental retardation is a critical period in the lives of the parents, as evidenced by a review of the literature. Other moments in the life of the child are also critical, traumatic and joyful. This paper does not examine the growing-up years, the school years, where the person with mental retardation strives toward his or her potential with joy and sorrow nor discuss the great love and dedication of parents and professionals. They live with, play with, grow with, enjoy

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[1] Boyd, "The Three Stages in the Growth of a Parent of a Mentally Retarded Child," p. 611.

life with, and suffer ups and downs with the unique individual who has a name, a personality, and a developmental disability called mental retardation. The author recognizes the importance of these experiences and suggests to the reader that they be kept in focus as the following sections of this paper consider other critical and traumatic periods in the life of the child who has mental retardation. One of these, terminal illness or pre-death, will be discussed in the following section of this paper.

Pre-Death

Each person with a developmental disability such as mental retardation, comes to his or her death in a different way, just like other persons. Some persons with mental retardation die at birth or soon thereafter; some after the first years of life; some in the teenage years; some in their young adult life; some in the middle years and some after a long life. Some have been critically ill all their lives, short or long. Some have a heart defect and, even though they live a very active life, they are never far away from death. Some develop an infection such as pneumonia and die after a short illness. Others die after an accident or severe injury. Others die peacefully after a long life. It is no exaggeration to say that death comes in as individualistic a manner as the individual herself or himself.

However death can be classified into three time frames: (a) death expected after a long life; (b) sudden and unexpected death with little or no illness; (c) death after a chronic or extended illness. Each of these death sequences will cause different reactions in those who are living. With regard to the first sequence, the parents of the person with mental retardation may have already died, and those who visit or mourn are brothers or sisters. In the second, the reactions are shock, disbelief and numbness. The reactions too, and impact of, the third are many and varied. The experience identified as pre-death is more evident here and this paper will review the literature regarding crisis and adaptation in the families of children with fatal, malignant or chronic illnesses.

The impact of death on normal family life has been abundantly discussed in the literature. Much of present-day knowledge of the family's reactions to death and pre-death has been derived from studies involving some progressive illness in the child such as leukemia. Friedman proposed that mourning was less intense if prepared for during the slow process of dying from chronic illness.[1] Yudkin disagrees.

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[1] Stanford B. Friedman, "Behavioral Observations on Parents Anticipating the Death of a Child," Pediatrics 32 (October 1963):610-625.

> Perhaps we are more able to help the parents of a child who has been killed in an accident than those of a child who is dying of an illness: the first is someone else's responsibility; death from disease we think of as ours.[1]

The literature indicates that most of the parents who are faced with chronic sorrow or terminal illness will, prior to the death, prepare for the inevitable loss by what the authors call "anticipatory mourning." Gourevitch describes it as follows:

> While still alive, the child is subjected to a progressive withdrawal of cathexis, a detachment that takes the guise of philosophic resignation. This is associated with denial, a defense mechanism that appears in the form of stubborn hope, often incompatibly linked with a clear knowledge of prognosis, accepted at the conscious level.[2]

Futterman and Hoffman defined anticipatory mourning as:

> A set of processes that are directly related to the awareness of the impending loss, to its emotional impact and to the adaptive mechanisms whereby emotional attachment to the dying child is relinquished over time.[3]

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[1] Stephen Yudkin, "Children and Death," Lancet (January 1967):38.

[2] Michel Gourevitch, "A Survey of Family Reactions to Disease and Death in a Family Member," in The Child in His Family, Vol. 2 The Impact of Disease and Death, ed. E. James Anthony (New York: John Wiley and Sons, 1973), p. 25.

[3] Edward H. Futterman and Irwin Hoffman, "Crisis and Adaptation in the Families of Fatally Ill Children," in The Child and His Family, Vol. 2 The Impact of Disease and Death, ed. E. James Anthony (New York: John Wiley and Sons, 1973), p. 130.

They identify five interwoven, evolving and interdependent processes in anticipatory mourning. They are: (1) acknowledgment; (2) grieving; (3) reconciliation; (4) detachment; and (5) memorialization. These are described by the authors:

> Acknowledgment . . . entails the progressive realization by the parents that the child's death is inevitable. It involves the continual struggle between hope and despair with progressive deepening of parental awareness and narrowing of hope.
>
> Grieving . . . includes the experience and expression of the emotional impact of the expected loss along with the physical, psychological and interpersonal turmoil associated with it. Initial undifferentiated reactions gradually give way to more stable and controlled patterns. . . . Grieving fluctuates with life contingencies and with the course of the illness, but gradually mellows in quality and diminishes in intensity.
>
> Reconciliation . . . refers to the process of developing a perspective about the child's anticipated death, which preserves the parents' sense of confidence in the worth of the child's life and of life in general. Among the adaptive responses included in reconciliation are redefining the implications of the child's death, seeking consolation from the past or present life of the child and counting blessings.
>
> Detachment . . . denotes the process by which parents withdraw emotional investment from the child as a growing being with a real future. . . . The timing of detachment is related to the parent's evolving concepts of the child's life expectancy.
>
> Memorialization . . . is the process whereby parents develop a relatively fixed mental representation of the dying child which will endure beyond his death. This process includes progressive abstraction by which parents increasingly think of the child in global terms rather than in relation to specific behaviors and progressive idealization (euologization). Idealization sometimes takes the extreme form of enshrinement whereby the child is conceived of as possessing other-worldly characteristics.[1]

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[1] Ibid., p. 131.

Chodoff, Friedman and Hamburg described the adaptational behaviors of forty-six parents of twenty-seven children under treatment for leukemia or other malignant diseases. They mentioned the phenomenon of anticipatory mourning and reported that:

> The process of anticipatory mourning can be seen very clearly in the parents of leukemic children, especially if the child's illness lasts for at least three to four months. Its development is closely connected with the change from a purely intellectual to an emotional acceptance of the fatal nature of the child's disease and with a gradual curtailment and constriction of hope. As grief appeared, the parents displayed the usual somatic signs and became preoccupied with thoughts of the ill child. As time passed, however, there was a gradual detachment of investment from the child, who became less a real object than, in a sense, already a memory while still alive, leading to an attitude of philosophical resignation which enabled the parents to react to the actual terminal phase and death in a much more muted fashion than if death had occurred without this kind of preliminary mourning work.[1]

Do the parents of the child with mental retardation, who is terminally ill, experience anticipatory mourning? There is no specific reference to it in the literature. However, in an article on the family of the dying child, Easson mentions the mourning reaction, and does not specify the condition of the child.[2] So it would seem that if the child is dying, retarded or not, the parents would experience

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[1] Paul Chodoff, Stanford B. Friedman, and David A. Hamburg, "Stress, Defences and Coping Behavior: Observations in Parents of Children with Malignant Disease," American Journal of Psychiatry 120 (February 1964):747-748.

[2] William M. Easson, "The Family of the Dying Child," Pediatric Clinics of North America 19 (November 1972):1157-1165.

anticipatory mourning. He describes the mourning reaction as, "the special reaction to approaching death."[1] He considers it under three headings: (a) sadness; (b) anger; (c) reinvestment.

> The sadness of mourning is the sadness of loss. A feeling of emptiness. A sense of loneliness. The sadness of mourning is the sadness for that child, who is going to die and the sadness for those of us who still live but die eventually. . . . In western culture, mourning anger is usually not understood or tolerated, but nevertheless anger is always present. If the dying child has been meaningful in any way to this family, they have now to readjust their lives and they have reason to be angry at this readjustment. If they have cared for him, they will miss the happiness he has brought and they have a right to be angry now that he is leaving them. If they have rejected this child, his approaching death is disturbing them just one more time and they have a cause to be angry. If these parents had any hopes for their child, these hopes are now dying with the child and they will feel anger. If they had any dreams about their child's future, these dreams are fading and the parents feel understandable resentment. . . .
>
> During normal mourning process the mourners gradually withdraw their emotional investment in the person who is dying and reinvest their energy in the world that will live on. This process of emotional reinvestment is usually gradual and occurs over several months, but where the emotional bonds have been minimal, the family withdrawal can be sudden and very complete. When the ties between the child and his family have been fraught with pain, anxiety and anger, these relationships are more readily ended and the family finds it easier to reinvest elsewhere.[2]

The author also stresses the point that if the child is very young, or has been sick from birth or from early infancy, or if repeated or chronic illness have kept the

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[1] Ibid., p. 1160.

[2] Ibid., pp. 1160-1161.

child away from home, "the mourning family may have separated emotionally from him long before his last illness so that they have very little interest in him even though he is now finally dying."[1]

This would seem to have special meaning for the parents of a child with severe or profound mental retardation, who has been chronically ill since birth and has been placed in a special care center.

Hansen indicated that the mourning process begins with the pronouncement of the fatal disease.[2] This viewpoint reflects that of other authors cited in this paper who indicated that the parents go through a mourning process at the birth of a child with mental retardation. The same question can be asked that Hansen asks: "If we accept approximately one year as usual for the work of mourning, what then occurs when the mourning work has been partially satisfied and the mourned one yet survives?"[3]

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[1] Ibid., p. 1162.

[2] Howard Hansen, "Discussion-To Jimmy. A Clinical Case Presentation of a Child With a Fatal Illness," in The Child in His Family, Vol. 2 The Impact of Disease and Death, ed, E. James Anthony (New York: John Wiley and Sons, 1973), pp. 185-187.

[3] Ibid., p. 186.

The author briefly answers his own question:

> Ambivalence results, and that ambivalence seems reasonably well substantiated in the reactions of family members in the case presented. Decathexis [deconcentration of the amount of desire] of the loved object occurs gradually whether the loss is relative or in fact. This factor complicates the clinical course and management of fatal illness of unpredictable duration.[1]

Easson also seems to answer the same question when he states:

> Dying is often a longer process now. Medical and surgical procedures are more successful and the younger patients linger on. The doctor and the nurse can slow or arrest the illness process, but they may not be able to delay the process of mourning. Very often the treatment team has to deal with dying children and mourning family, where the family reinvests elsewhere before the child is actually dead. Physically the child continues to live, but emotionally he is dead to his family--a living death. During the whole treatment process the doctor must work with the child's family to maintain their involvement with the child. He should be aware when the family members are loosening their emotional ties. He may then wish to encourage the treatment team to move closer to the child to take the place of a family that has mourned and reinvested too soon.[2]

The second phenomenon that takes place during the pre-death period is called "maintenance of confidence." It is defined by Futterman and Hoffman as, "The set of processes which facilitates parents' sense of worth, trust and mastery in the face of potential guild, rage and helplessness."[3]

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[1] Ibid.

[2] Easson, "The Family of the Dying Child," p. 1162.

[3] Futterman and Hoffman, "Crisis and Adaptation in Families of Fatally Ill Children," p. 132.

These processes, according to the authors, evolve and interact throughout the course of the illness and after the death of the child. They are: (1) mastery operations; (a) search, (b) participating in care; (2) maintenance of equilibrium; (3) affirmation of life; (4) reorganization. The authors felt that when a chronic disease such as leukemia takes hold of a child:

> Most parents do everything possible to master the disease. During the child's illness, the mastery operations are buttressed by hope for prolongation of life and for total cure. After his death, activities may broaden to encompass afflictions in others within and beyond the family. Included in mastery operations are search for knowledge and resources and participation in the medical care of the child.[1]
>
> Most parents strive to prolong life until the last moment. On the other hand, the parents' longing to be relieved of their burdens and their wish to see their child spared from further suffering make caring for him particularly conflict-ridden toward the end. When asked how she felt when her child cried in pain, one mother admitted, "I would just like to take a shotgun and get it over with."[2]

The authors discuss maintenance of equilibrium in terms of keeping to familiar routines, continuation of usual patterns of family behavior and of reaching out for emotional support. They also discuss it in terms of regulating expression of feelings.

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[1] Ibid. , p. 132.

[2] Ibid., p. 136.

> We found that feelings, in general, were monitored, regulated and modified by the parents in the service of maintaining equilibrium. Erecting a facade of calm acceptance was used for concealing anguish, protecting others, protecting themselves and preserving functioning. Parents usually avoided crying in front of children, minimized displaying anxiety in the presence of neighbors and relatives, shielded the physician from their rage and underplayed their fears and doubts before each other.[1]

The authors make an important point, which could serve as a guideline for all who are working with parents who have a child who is chronically ill.

> In our experience, parents often found that family members and helping professionals, such as ministers, nurses and mental health workers, were more likely to advocate either unrelenting cheerful hope for survival or resigned acceptance of the child's anticipated death than to recognize the legitimacy of the parents' rage and grief and to foster expression of these feelings.[2]

The third process in the maintenance of confidence, the affirmation of life is manifested:

> . . . in the prevalent devotion by parents to making the most of the child's life in the face of full acknowledgment of his fatal prognosis . . . . Much of their affirmation took the form of counting their blessings whereby they asserted that the emotional investment in living was worth the risks, despite the loss they were enduring.[3]

The fourth process, reorganization:

> . . . entails a revision of values, goals, and philosophy of life in the light of the sickness and death of the child.

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[1] Ibid., pp. 137-138.

[2] Ibid., p. 138.

[3] Ibid., p. 139.

> . . . involves a change in orientation toward time. Parents developed a heightened sense of immediacy and tendency to savor the present during the course of the child's illness and dying, which frequently persisted after his death.[1]

The authors in the conclusion of their study indicate that a maladaptive outcome was quite rare for the parents in the study. They make a statement which has great consequence especially when applied to the parents of the child with mental retardation:

> Those who were able to accomplish the task of anticipatory mourning were also able to deal with the dilemmas related to the threat to their sense of mastery, worth and trust and to maintain confidence during the child's illness and after his death. To the degree that reorganization occurred parents responded to the crisis not only with adaptive measures which maintained equilibrium or restored coping and defensive operations, but also with liberation of latent potentialities resulting in further maturation and new adaptive capacities.[2]

This paper has discussed anticipatory mourning and maintenance of confidence as described in the literature regarding pre-death. Those parents whose child has multiple defects and complications at birth, or who are faced with very serious medical complications later in life, face other concerns such as whether to perform surgery, or whether the person be allowed to live or die. Duff and Campbell outlined the problem and dilemma involved.

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[1] Ibid., pp. 140-141.

[2] Ibid., p. 142.

> Of 299 consecutive deaths occurring in a special-care nursery, forty-three (14 percent) were related to withholding treatment. In this group were fifteen with multiple anomalies, eight with trisomy, eight with cardio-pulmonary disease, seven with meningomyelocele, three with other central nervous system disorders and two with short-bowel syndrome. After careful consideration of each of these forty-three infants, parents and physicians in a group decision, concluded that prognosis for meaningful life was extremely poor or hopeless, and therefore rejected further treatment. The awesome finality of these decisions combined with a potential for error in prognosis made the choice agonizing for families and health professionals. Nevertheless the issue has to be faced, for not to decide is an arbitrary and potentially devasting decision of default.[1]

A recent study by Todres et al., regarding pediatricians' attitudes affecting decision making about defective newborns; found that pediatricians view the parent as the final decision maker.[2] The majority supported the right of the parents to withhold consent for the performance of surgery:

> This view is supported by a recent World Health Organization report concerning newborns with congenital defects. ". . . it is suggested as a general rule that the decision should be that of the parents, the role of physician being to explain to them as accurately as possible the consequences of the available options." This WHO recommendation and our results appear to recognize the responsibility and authority of family members to make health-related decisions on their behalf.[3]

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[1] Raymond S. Duff and A.G.M. Campbell, "Moral and Ethical Dilemmas in the Special-Care Nursery," The New England Journal of Medicine 289 (October 1973):890.

[2] David Todres, Diane Krane, Mary C. Howell and Daniel C. Shannon, "Pediatricians' Attitudes Affecting Decision-Making in Defective New-Borns," Pediatrics 60 (August 1977):197-201.

[3] Ibid., p. 201.

How can the parents come to a decision that they can live with? The reader is referred to a comprehensive work by Weber on the subject.[1] He presents and discusses the positions taken by four well known ethicists: David Smith, Joseph Fletcher, Warren Reich and Richard McCormick on the questions of if and when there is legitimate reason not to work for the survival of the severely handicapped infant. Smith[2] believes that withholding treatment is wrong, unless it can be argued that the action is necessary to protect personal life of at least one specifiable other or the infant cannot receive care in any other form.

Fletcher is cited as arguing a very different position.[3] He insists that at times it is proper to bring about the death of a child with severe retardation, and that no other course of action could be considered responsible in some circumstances. He argues that some lives are not as human or as valuable as others. He proposes that infants who will never be capable of truly human functions, are not truly human and it is not killing a human person to kill them.

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[1] Leonard J. Weber, Who Shall Live (New York: Paulist Press, 1976), pp. 7-133.

[2] David Smith, cited by Leonard J. Weber, Who Shall Live, p. 61.

[3] Joseph Fletcher, cited by Leonard J. Weber, Who Shall Live, pp. 63-65.

Reich takes the position that there is, in some cases, a moral difference between withholding treatment (even though the baby dies as a result) and directly killing.[1] Letting die may be proper at times.

McCormick is quoted as proposing that:

> The guideline is the potential for human relationships associated with the infant's condition. If that potential is simply non-existent or would be utterly submerged and underdeveloped in the mere struggle to survive, that life has achieved its potential. There are those who will want to continue to say that some terribly deformed infants may be allowed to die because no extraordinary means need be used. Fair enough. But they should realize that the term extraordinary has been so relativized to the condition of the patient that it is this condition that is decisive. The means are extraordinary because the infant's condition is extraordinary.[2]

Weber himself proposes that the parents are to make the final decision, keeping in mind the following guidelines which he gives:

> Every handicapped child should be treated unless:
>
> (1) The treatment is not likely to be successful, that is, the child is not expected to live for more than a few months even with the best of treatment.
> (2) The treatment imposes an excessive burden on the child. For example, he can expect a very long period of intensive fighting for life or the treatment itself results in a severe and permanent handicap.
> (3) The treatment imposes an excessive burden on the family. Such would be the case if treatment placed the continued existence of the family as a functioning unit in very serious jeopardy.[3]

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[1] Warren Reich, cited by Leonard J. Weber, Who Shall Live, pp. 66-67.

[2] Richard McCormick, cited by Leonard J. Weber, Who Shall Live, p. 69.

[3] Weber, Who Shall Live, pp. 97-98.

The parents can base their decision on the sanctity of life, or the quality of life of their child. They can turn off, or turn on, the extraordinary means of care that keep their child alive. They can request or deny the surgical treatment that may or may not benefit the child or the family. But whatever they do, their decision will be influenced by their attitude about the next stage of the ill person's life--death.

Before discussing the next phase, attitudes to and the meaning and consequences of death, a pastoral area will be considered. That is the anointing of the sick.

Anointing of the Sick

Article 73 of the Constitution on the Sacred Liturgy states:

> Extreme Unction, which may also and more fittingly be called Anointing of the Sick, is not a sacrament for those only at the point of death. Hence, as soon as any one of the faithful begins to be in danger of death from sickness or old age, the fitting time for him to receive this sacrament has already arrived.[1]

In the fifth chapter of the Letter of James, he tells the Christians, "Is there anyone sick among you? He should ask for the presbyters of the church. They in turn are to

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[1] "The Constitution on the Sacred Liturgy," in Vatican Council II. The Conciliar and Post Conciliar Documents, ed. Austin Flannery (Collegeville, Minnesota: The Liturgical Press, 1975), p. 22.

to pray over him, anointing him with oil in the Name of the Lord."[1]

Should the person with mental retardation who is very young or has severe or profound mental retardation receive the Sacrament of the Anointing of the Sick? The answer is contained in a simple pastoral guideline proposed by Schmitz and Tierney:

> A sick child may be anointed, providing the child has sufficient use of reason to be comforted and uplifted by the sacrament. However, any child who is dangerously ill should always be anointed.[2]

Conheeney reviewed the history and advantages of this sacrament for persons with mental retardation.[3] She proposed that the administration of the sacrament of the Anointing of the Sick be available to persons with mental retardation in the context of the ministry of Jesus who presented the Good News for all persons.

Rahner explained what the Sacrament of the Sick means for the Christian.

> . . . in virtue of this sacrament, man will endure this situation of life in a Christian manner, either because the sacrament restores his bodily health, or because it

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[1] James 5:14 (NAB).

[2] Walter J. Schmitz and Terence E. Tierney, Liturgikon (Huntington, Indiana: Our Sunday Visitor, 1977), p. 148.

[3] Noreen H. Conheeney, "The Value of the Sacrament of the Sick for Mentally Retarded Persons," (MA Research Paper, Cardinal Stritch College, Milwaukee, 1979), pp. 1-31.

> enables him to accept his mortal illness in a Christian manner and hence to die in the Lord. . . . this sacrament thus receives the character of a consecration to death. It becomes the visible manifestation of the fact that the Christian, confirmed by his anointment in the Lord, in virtue of his grace, faces the last trial of his life, performs its last act, his own death, in companionship with the Lord.[1]

The literature on pre-death has been reviewed. It has dealt with anticipatory mourning and with maintenance of confidence as part of the reactions and feelings of the parents and family of the ill person. The question of surgery and whether to allow the child with severe anomalies to die were discussed. The Sacrament of the Sick, its administration and reception by the person with mental retardation, was examined.

In the following section a review of the literature in regard to attitudes toward death and the meaning of death from a secular and religious viewpoint will be attempted.

Death of the Person with Mental Retardation

It would seem that this paper has made a full circle; the phone is heard, the doctor's voice explains to all present, "I am sorry, this person is dead."

However, since this paper is concerned with the death and burial of the person with mental retardation and the effects on the parents, it was necessary to take a close

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[1] Karl Rahner, On the Theology of Death (New York: Herder and Herder, 1962), p. 86.

look at the parent's feelings and reactions at the birth, as reported in the literature. As the reader will recall, they have gone through, or are still going through, the feelings, emotions and reactions involved in denial, anger, negotiation, withdrawal and acceptance or rejection of their child. They have gone or are going through, according to some authors, the process of mourning. They have experienced or are experiencing chronic sorrow or death wishes, following the diagnosis of profound, severe or moderate mental retardation in their child, their son or daughter. Possibly a resulting theological crisis may have had a profound effect on their lives. If their child has been chronically ill or had multiple defects and complications, the parents may be in, or have completed, the process of anticipatory mourning and maintenance of confidence. If there had been a question of whether to operate or not the decision was made and now the question is no longer moot. Whether parents have experienced any or all of the above feelings, they now are faced with a reality that generates feelings and reactions, the reality that their son or daughter is dead.

Whether this son or daughter who had profound, severe, or moderate mental retardation, lived a long or short life, suffered much or little, died unexpectedly or after an extended terminal illness, the reality is still the same, the person is dead. The question for the parents, friends and the reader now becomes, "Where do we go from here?" The answer to this question may well depend on the attitude one has toward death and its meaning.

This section will therefore review the literature regarding prevalent attitudes toward death before discussing the funeral, the burial and the grief associated with the death of a family member. According to Braga and Braga:

> Death is a subject that is evaded, ignored and denied by our youth-worshipping, progress-oriented society. It is almost as if we have taken on death as just another disease to be conquered. But the fact is that death is inevitable. We all will die; it is only a matter of time. Death is as much a part of human existence, of human growth and development, as being born. It is one of the few things in life we can count on, that we can be assured will occur. Death is not an enemy to be conquered or a prison to be escaped. It is an integral part of our lives that gives meaning to human existence. It sets a limit on our time in this life, urging us to do something productive with that time as long as it is ours to use. This then is the meaning of death, the final stage of growth. All that you are and all that you've done and been is cluminated in your death.[1]

Kubler-Ross in all her works on death, and especially in her latest, attempts to convey two important messages regarding death to her readers:

> . . . Death does not have to be a catastrophic, destructive thing; indeed, it can be viewed as one of the most constructive, positive, and creative elements of culture

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[1] Joseph L. Braga and Laurie D. Braga, "Foreward," to Death, The Final Stage of Growth, by Elisabeth Kubler-Ross (New Jersey: Prentice-Hall, Inc., 1975), p. x.

> and life. . . . Namely, that all people are basically alike, they all share the same fears and the same grief when death occurs.[1]

Later in her work she states:

> Death is the key to the door of life. . . . Death is the final stage of growth in this life. There is no total death. Only the body dies. The self or spirit or whatever you may wish to label it, is eternal . . . . Death, in this context, may be viewed as the curtain between the existence that we are conscious of and the one hidden from us until we raise that curtain.[2]

Many authors have written about death and its meaning. Fowles gleams from the works of Heraclitus of the fifth century B.C. and others, some perspectives on death:

> We hate death for two reasons. It ends life prematurely and we do not know what lies beyond it. Our second hatred of death is that it always comes too soon. . . . The function of death is to put tension into life, and the more we increase the length and the security of individual existence then the more tension we remove from it . . . . There are two tendencies in the twentieth century, . . . to domesticate death, to pretend that death is like life; the other is to look death in the face. . . . Death is in us and out side us: beside us in every room, in every street, in every field, in every car, in every plane. . . . Being dead is nothingness, not-being. . . . The more absolute death seems, the more authentic life becomes. . . . Death contains me as my skin contains me. . . . Because I am a man, death, is my wife; and now she has stripped, she is beautiful, she wants me to strip, to be her mate.[3]

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[1] Elisabeth Kubler-Ross, Death, The Final Stage of Growth (New Jersey: Prentice-Hall, Inc., 1975), p. 2.

[2] Ibid., pp. 164-166.

[3] John Fowles, "Human Dissatisfactions," in Death, Current Perspectives, ed. Edwin S. Shneidman (Palo Alto, California: Mayfield Publishing Co., 1976), pp. 3-5.

The scope of this paper could not sufficiently encompass the cultural perspectives of death as presented in the literature. The reader is referred to Death, Current Perspectives for a more detailed and thorough review.[1]

It suffices for the purposes of this paper to refer to the introduction to part one of the above mentioned work. Shneidman gives a summary of the various views presented.[2] He refers to death as perhaps man's greatest mystery and source of fear. Man's thoughts about death have influenced his philosophies and his religions. He points out that man seems to generate, in his various cultures, some kind of view of death or strategies for dealing with the idea of death. These strategies are functionally related to, or even functionally dependent on, the culture's religions, philosophies, legal and political institutions and socio-economic conditions at a particular time. Man's views of death and beyond are expressed through a tragic hunger for immortality to a total disbelief in anything beyond the grave. The author sums up these ideas when he writes:

> Death is destroyer and redeemer; the ultimate cruelty and the essence of release; universally feared but sometimes actively sought; undeniably ubiquitous, yet

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[1] Edward S. Shneidman, ed., Death, Current Perspectives (Palo Alto, California: Mayfield Publishing Co., 1976), pp. 2-542.

[2] Ibid., pp. 10-12.

> incomprehensively unique; of all the phenomena, the most obvious and the least reportable, feared yet fascinating.[1]

Most of the well-known religions of the world deal with death in their customs, beliefs and religious practices. Two of these religious traditions, the Jewish and Catholic, will be considered in the following pages.

Reimer states, "the Jewish way of death is different, just as the Jewish way of life is different. To capture it in a couple of phrases is impossible. Every summary is a distortion. But there are certain underlying principles. . . ."[2] The underlying principles stem from the realism of Judaism which knows that death is part of each man's life and that self-deception does no good. The principles are based on the prayers to be said when dying:

> I acknowledge before thee, O Lord my God and God of my Fathers, that my life and death are in thy hands. May it be thy Will to heal me. But if death is my lot, then I accept it from thy hand with love. May my death be an atonement for whatever sins and errors and wrongdoing I have committed before thee. In thy mercy grant me of the goodness that is waiting for the righteous, and bring me to eternal life. Father of the orphans, Protector of the widows protect my loved ones with whom my soul is bound. Into thy hands I return my spirit. Thou wilt redeem me, O ever faithful God, Hear O Israel, the Lord our God, the Lord is one.[3]

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[1] Ibid., p. 12.

[2] Jack Riemer, ed., Jewish Reflections on Death (New York: The Jewish Publication Society of America: Schocken Books, 1974), p. 9.

[3] Ibid., p. 10.

The principles are reflected in the Jewish practice of writing ethical wills, in which the individuals tried to summarize the faith they had lived by and the goals they wanted their children to cherish. Gordon puts it another way:

> The Jewish tradition seasoned by centuries of experience in suffering and surviving, provides a network of ways in which to affirm life in the face of death. It is a tradition that contains the wisdom which enables us to express our grief, to strengthen our family and community ties, to honor God, and to accept His will.[1]

There are many Catholic authors who treat the subject of death in their works. Rahner discusses the subject under three headings: (a) death as an event concerning man as a whole; (b) death as a consequence of sin; (c) death as a dying with Christ.[2]

> Through biological death, man achieves his final constitution. This death is neither the end of his existence, nor is it a mere passage from one form of existence to another . . . . Death is the beginning of eternity, . . . The total created reality of the world grows in and through persons having body and spirit, and the world is, in a certain sense, the body of those persons. Their death slowly brings the universe to its final stage. . . . Death thus must be both of these. As the end of man, who is a spiritual person, it is an active consummation from within brought about by the person himself. It is a growing up, the result of what man has made of himself during life, the achievement of total self-possession. . . . At the same

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[1] Audrey Gordon, "The Psychological Wisdom of the Law," in Jewish Reflections on Death, ed. Jack Riemer (New York: The Jewish Publication Society of America; Schocken Books, 1974), p. 103.

[2] Rahner, On the Theology of Death, pp. 7-89.

> time, death is the end of the biological life. It strikes man with one blow which cannot be resolved into a number of partial causes; it strikes him in its totality, breaking him up from without. It is destruction, an event overcoming man from without, unexpectedly.[1]

Death as a consequence of sin is explained by Rahner:

> Actual death becomes a visible demonstration of the fissure between God and man, which cleaves man's being to its very essence and which was opened at the very beginning of his spiritual history. Because man has lost the divine life, rooted in union with God by grace, his earthly existence also disintegrated. Man's death is the demonstration of the fact that he has fallen away from God.[2]

Death as dying with Christ is expained by Rahner as:

> . . . not only a manifestation of sin, but also a revelation of our participation in the death of Christ, culminating in the appropriation of his redemptive death by mortal men.[3]

Boros presents the Catholic position in another way when he says:

> Death gives man the opportunity of posing his first completely personal act: death is therefore, by reason of its very being, the moment above all others for the awakening of consciousness, for freedom, for the final decision, about his final destiny.[4]

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[1] Ibid., pp. 37-39.

[2] Ibid., pp. 41-42.

[3] Ibid., p. 64.

[4] Ladislaus Boros, The Mystery of Death (New York: The Seabury Press, 1965: A Crossroad Book, 1973), p. ix.

Nowell takes the same position and elaborates on Boros' hypothesis of the final decision.

> At the moment of death, the human person is set free from all limitations which in this life cloud our decisions, and is thus able to make the kind of choice toward which we aspire, but which we are never actually to achieve, one unencumbered by distractions and conditioning and one at the same time made in complete knowledge of what is involved . . . . But if death represents our final and definitive encounter with God, then it means encounter with the full light of truth, and thus with the ability at last to decide in full knowledge of what is involved. Further it means for the first time a full encounter with ourselves, with all those sides of our personality that normally remain hidden and are not fully and completely exposed to awareness even under the most searching analysis.[1]

Greeley presents death in the context of a spring festival and the death of a Christian in the context of Easter.

> Easter is the Christian spring festival. It does not even provide a new answer; there always has been a strong hunch in human nature that death does not say the final word. What the Christian spring feast adds is the power of its certainty that death is not ultimate. The resurrection of Jesus says to the Christian, and through him the rest of humankind, "Dream your most impossible dreams, fantasize your maddest fantasies, hope your wildest hopes, and when they all come to an end, what the Heavenly Father has prepared for you only begins, for eye has not seen nor has ear heard, nor has it entered into the heart of man what God has prepared for those who love Him."[2]

This paper has discussed attitudes toward death from a secular and religious viewpoint where it is described

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[1] Robert Nowell, What a Modern Catholic Believes About Death (Chicago: The Thomas More Press, 1972), p. 43.

[2] Andrew Greeley, Death and Beyond (Chicago: The Thomas More Press, 1976), p. 20.

as nothingness, non-being, man's greatest mystery and source of fear, a destroyer and a redeemer, the ultimate cruelty, the essence of release, a part of each person's life, an atonement for sins and errors, an event concerning man as a whole, a consequence of sin, a dying with Christ, the beginning of eternity, an opportunity for man to pose his first final and completely personal act, the moment for the encounter with God, the hypothesis of the final decision, a full encounter with self. Death is not the ultimate because of the resurrection of Jesus.

But a question remains in the context of this paper. What is death for a child or young person who has profound, severe or moderate retardation? What does death mean to the parents and friends of the person who had mental retardation and is now dead?

Boros, cited earlier, speaks to this subject when he discusses infants, and it can be inferred that he would also mean those persons with profound, severe or moderate retardation.

> In the hypothesis of a final decision even infants would be able to make their decision in full liberty and knowledge at the moment of death. It must not be forgotten that infants who die before they come to the use of their mental and spiritual faculties are nevertheless creatures endowed with spirit, and they, like all human beings, awake in death to their full liberty and complete knowledge. In death they too are brought face to face with the essential dynamism of their spirit and

> also with the basis of the world, and in this confrontation meet their redeemer. . . . In death the infant enters into full possession of his or her spirituality, i.e., into a state of adulthood that many adults themselves never reach during their lifetime. The result of this is that no one dies as an infant, though he may leave us in infancy.[1]

Gregory of Nyssa, who died in 394 A.D., said basically the same:

> The soul that has tasted neither of virtue nor indeed of the evils of wickedness, inasmuch as it has not begun to encounter the disease of evil, remains without a share in that life which earlier we defined as the knowledge of God and participation in his life, but initially does have a share in proportion to its capacity for nourishment until, having been brought to maturity by contemplation of reality as if by some appropriate food, it becomes capable of the greater role, sharing abundantly in ultimate reality according to its ability.[2]

This section has considered the major attitudes and meanings of death as expressed in the literature. The person is dead. Now what? The next section will deal with the after-death, the funeral and burial.

The Funeral of the Person with Mental Retardation

The previous section dealt with the death of the person with mental retardation and reviewed the literature about secular and religious attitudes to, and meaning of,

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[1] Boros, The Mystery of Death, pp. 109-110.

[2] Gregory of Nyssa, quoted in Robert Nowell, What a Modern Catholic Believes About Death (Chicago: The Thomas More Press, 1972), p. 58.

death. The question was posed, now what? This section will review the literature about the after-death process to assist the reader, parents, family and friends in dealing with it.

What does one do when someone dies? There are many procedures which hospital staff must follow. The reader is referred to the directives and procedures followed at Pacific State Hospital and Development Center contained in Appendix A of this paper. They are detailed and cover the duties of the doctor, nurse, program director, social worker, chaplain and others at the death of a resident/patient who has mental retardation.

If the family has not been present at the death, or if the death was sudden, how does the person who must break the news best help the family accept the death? Kubler-Ross answers this question:

> You cannot help a family to accept death at the moment you give the bad news. All you can do is stay with the family, allow them to cry on your shoulder, to question God, and, if necessary, be angry at God or at the hospital staff without your trying to put the brakes on, and without discouraging them from using angry and not always comfortable language.[1]

The author goes on to say that the family will go through the five stages that the dying patient goes through. These are, as has been mentioned previously in this paper, a stage of shock and denial, followed often by tremendous

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[1] Elisabeth Kubler-Ross, Questions and Answers on Death and Dying (New York: Macmillan Co., 1974, Macmillan Paperbacks, 1977), p. 140.

anger, a brief period of bargaining and a prolonged stage of depression and, hopefully, acceptance. When dealing with family after death has occurred, Kubler-Ross states:

> Once the patient dies, I find it cruel and inappropriate to speak of the love of God. When we lose someone, especially when we have little if any time to prepare ourselves, we are enraged, angry, in despair; we should be allowed to express these feelings. The family members are often left alone. . . . Bitter, angry, or just numb, they [are] unable to face the brutal reality. The first few days may be filled with busywork, with arrangements and visiting relatives. The void and emptiness is felt after the funeral, after the departure of the relatives. It is at this time that family members feel most grateful to have someone to talk to. . . . This helps the relative over the shock and the initial grief and prepares him for a gradual acceptance.[1]

As was previously discussed in this paper, Ogg also mentions that there are distinct phases in normal bereavement, which lasts longer for some people than for others and which may overlap. They are:

> Shock and numbness; disbelief and illusions; a time of inner conflict; the burden of guilt; feelings of anger; aloneness; expressing grief . . . delayed, inhibited and chronic grief are three kinds of extreme reactions that seriously hamper working through grief, to a stage of acceptance and reintegration.[2]

Mourners go through the syndrome of bereavement. Lindemann indicates that normal grief includes waves of somatic distress lasting from twenty minutes to an hour;

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[1] Kubler-Ross, On Death and Dying, p. 177.

[2] Ogg, A Death in the Family, pp. 2-7.

a tightness in the throat; frequent crying and sighing; a feeling of emptiness, weakness and tension; a sense of heaviness, fatigue and a lack of appetite; a preoccupation with death and the deceased; a distance from and a loss of warmth for other people, including a tendency to respond with irritation and anger, and to handle others in a stiff formal manner; much talking about the deceased; a realization that a large part of the person's customary activity was done in some meaningful relationship to the deceased and now it has lost its significance.[1] Significantly Lindemann found that if the mourner lets himself or herself experience the grief s/he can deal emotionally with the experience of loss in four to six weeks.

The after-death process moves through what Obershaw calls the "funeralization process, which encompasses all the activities from the time a death occurs until the family and friends have completed their help and supporting tasks and return to their daily lives."[2] He indicates that funerals, which have been around for over 60,000 years, have a strong social value, bringing together families, groups and entire nations to assist in the resolution of

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[1] Erich Lindemann, "Symtomatology and Management of Acute Grief," American Journal of Psychiatry 101 (September 1944):141-148.

[2] Richard J. Obershaw, Death, Dying, Grief and Funerals (Minneapolis, Minnesota: Grief Center, 1882 Hayes, Minn. 55418, 1976), pp. 3-30.

grief and the re-examination of social positions. He outlines the segments of the funeralization process: (1) the initial notification of death; (2) the counseling session with the funeral director; (3) the community notification of death; (4) the public visitation and viewing of the body; (5) Church service; (6) processional to the final place of disposition; (7) committal service; (8) post-funeral activities.

This paper will not involve itself with what constitutes each segment. The reader is referred to this brief work for more details.

One reference was found in the literature to the funeralization process after the death of a person with mental retardation. Because of its rarity and value it will be quoted at length. Nichols and Nichols preface their account of the funeral of a one year old boy who had Down's syndrome, by asking:

> Are needs met by avoidance or by spectatorship which permits denial? Or by hiring a functionary to do it all? Are needs really fulfilled by protecting from pain? Our choice isn't to avoid pain; our choice is only to permit pain to be experienced fast and hard or to be experienced slow and hard; that is our only choice.[1]

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[1] Roy Nichols and Jane Nichols, "Funerals: A Time for Grief and Growth," in Death: The Final Stage of Growth, ed. Elisabeth Kubler-Ross (New Jersey: Prentice-Hall, Inc., 1975), p. 94.

They then describe the funeral and burial:

> Keith, a mongoloid [Down's syndrome] child, died in his parents' car while they were returning from a week long vacation. Keith had caught a cold there and after consulting with their pediatrician, they started home. A swift invasion of pneumonia caused death to slam into Sue and Rob's lives totally unexpectedly.
>
> Our first meeting with Sue and Rob was for six hours while we listened to the purging of emotion; heard of the difficulties with police and physicians . . . who had investigated Keith's death; heard of the hostile reactions of wanting Keith to die when he was born fifty-three weeks ago (who wants a mongoloid child?); heard how they had counselled for months and studied mongolism and had grown to deeply cherish their Keith how they were preparing to structure their home and marriage to raise a retardate. Then baby Keith died. How insulting! The guilt, the pain, the shame. To have wanted his death, to have learned how to live, then to be faced with his death.
>
> Rob and Sue asked for an intense level of involvement. Sue was over seven months pregnant. Fetus Two would soon be in their lives and Fetus One was suddenly dead. Sue and Rob had about six weeks to resolve their grief and get ready to love Fetus Two. Rob's professional job of managing a group of computer programmers necessitated his clear thinking, his ability to handle not only people, but also to keep volumes of data and information orderly. Rob could not afford to trip over suppressed emotions and feelings while running the office. Rob and Sue decided to unload the pain fast and hard.
>
> The minister was especially selected for the specific task because he had a talent for speaking to the hurt. Rob and Sue made, for the funeral, a tape recording of personally meaningful folk music from their private collection of records. They chose to spend a whole morning with Keith's body--alone, before other people came. What they said, what they did, why they did it, only they and God and Keith know. But it helped. On the day of the funeral, after a very specific and skilled message by the minister, Rob and Sue closed Keith's little casket and held it in their laps as about forty friends went with them to the cemetery. They wanted honesty and realism so the grave was not concealed by artificial grass and the pile of dirt was not hidden. Rob and Sue, on their knees at the grave slowly, spontaneously, without any prior intent, placed Keith's body and casket into the grave and carefully began to pull dirt into the grave. The astute minister only said, "I think the kids need some help." Forty friends passed along the dirt,

> handful by handful, with no shovels, until the grave was filled. Then with dirt-caked hands, they heard the minister interpret to them what they had done, why they had done it, and what it meant to them.
>
> In four days, Rob and Sue had reached closure with Keith's sudden death. They continue to affirm the value of their choice to take the pain hard and fast. They purposefully continue to deal with emotions (it has been three months now) about Keith's life and death. Rob affirms that he is able to function well at work, free of the encumbrance of pent-up and repressed feelings.
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> . . . In death and in grief we do not need as much protection from painful experiences as we need the boldness to face them. . . . If we choose to love, we must also have the courage to grieve. . . . What a blessing to take the time to integrate loss into our lives so that when a love is lost our capacity to love is not lost also. From our grief can come growth.[1]

Speaking about parents' need to feel they have fulfilled their responsibility, Perske mentions the funeral of a person with mental retardation.

> One of the chaplains at our institution conducted the funeral service of a ten year old severely retarded child who lived on one of the wards. After the funeral, the parents had their final conversation with the chaplain. They felt the need to review the whole situation of their child from the time of his birth, early development, institutionalization, and the illness that caused his death. In the course of the conversation, the father said, "Chaplain, there's a lot of things we don't understand about Mike. And we never will. But, now that it's all over, I don't feel too bad. God knows we did everything we humanly could for Mike."[2]

The details of the funeral rite or practices will be different for different people or places. The scope of this paper could not properly describe funeral rites the

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[1] Ibid., pp. 94-96.

[2] Perske, "The Pastoral Care and Counseling of Families of the Mentally Retarded," p. 26.

world over. The reader is referred to Habenstein and Lamers' work on the subject.[1] The authors indicate that there is a belief in spirits or souls in perhaps every culture, but the beliefs about such souls are diverse, contradictory or confused. Some think there are four or a great many souls, others that there is just one. The soul is often viewed literally and is expected to escape through a hold in the roof, the pore of a hair or through a straw. Spirits or souls are said to rule the world, haunt the living, or go to a good or bad world. Funeral practices depend largely on these religious beliefs and on cultural practices. Mourning behavior may be absent or violent among different cultures. However most of the rituals and beliefs, however barbaric they may seem, that are found in other cultures are found also in Christian funeral practices.

One practice, that has significance for this paper, and is regarded by some to be a part of the funeral, is the practice of the viewing of the body.

Kubler-Ross feels that it is necessary only:

> . . . if the family has not been prepared for the death of their relative, as in the case of a sudden unexpected death. In this circumstance it is important that the

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[1] Robert Habenstein and William Lamers, <u>Funeral Customs the World Over</u> (Milwaukee, Wisconsin: Bulfin Press 1960).

> family can view the body before the funeral in order to face the reality of the beloved one's death. Otherwise, if there has been a prolonged illness, I regard the viewing of the body an unnecessary ritual.[1]

Baird echoes the same sentiments,

> Despite the trade's justification for viewing the body as a form of grief therapy, one finds evidence supporting it to be highly elusive. My own reaction to the painted restoration of my grandmother was that I thought it obscene, and this sentiment is mirrored by all I have spoken to. Jessica Mitford obtained similar reaçtions and, despite impressive research, found no psychiatric opinion that viewing the corpse contributed in any way to grief therapy. The North American continent is apparently the only place in the world where such a practice is tolerated.[2]

Obershaw expresses the opposite view and feels that it is a vital area of the funeralization process. He counsels families on the value of viewing the body in the open casket. If it is omitted it can be one of the most damaging aspects of the entire process.

> Viewing allows us to see the lost person, to realize again that death has taken place. This is important because it erases denial and . . ., it often initiates the emotional response to grief. The dead body is reality. It helps us to cry, to share our feelings and, as most authorities agree, this is vitally important to the total resolution of grief.[3]

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[1] Kubler-Ross, Questions and Answers on Death and Dying, p. 101.

[2] Jonathan Baird, "The Funeral Industry in Boston," in Death, Current Perspectives, ed., Edwin S. Shneidman (Palo Alto, California: Mayfield Publishing Co., 1976), p. 87.

[3] Obershaw, Death, Dying, Grief and Funerals, pp. 16-17.

The author also recommends public visitation, thus allowing the community to join in and share their sorrow.

Two funeral rites or passages will be reviewed: the Jewish rite and the Christian rite as expressed in the Catholic tradition.

According to Gordon, when death occurs Jewish law demands that immediate plans be made for burial, and the responsibility for all the funeral arrangements is placed upon the mourner.[1] He is released from the obligation to perform any positive religious commandments so that he may devote himself instead to those burial preparations and arrangements. According to Soloveitchik, there are two distinct and separate phases in the process of mourning for the Jewish people. The first phase begins with the death of the relative and ends with burial. It is called Ainut. The second, which is called Avelut, begins with the burial and lasts seven to sometimes thirty days.

> Ainut represents the spontaneous human reaction to death. It is an outcry, a shout, or a howl of grisly horror and disgust. Man responds to his defeat at the hands of death with total resignation and with an all-consuming masochistic self-devastating black despair.[2]

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[1] Audrey Gordon, "The Jewish View of Death: Guidelines for Mourning," in Death: The Final Stage of Growth, ed. Elisabeth Kubler-Ross (New Jersey: Prentice-Hall, 1975), pp. 44-51.

[2] Joseph B. Soloveitchik, "The Hallakhah of the First Day," in Jewish Reflections on Death, ed. Jack Riemer (New York: Jewish Publications, Schocken Books, 1974), p. 76.

> With the commencement of Avelut . . . the mourner undertake[s] an heroic task: to start picking up the debris of his own shattered personality and to re-establish himself as man restoring lost glory, dignity and uniqueness.[1]

According to the author, the turning point in the Jewish ceremony, the point where Ainut is transformed into Avelut, despair into intelligent sadness and self-negation into self-affirmation, is to be found in the recital at the grave of the Kaddish. This is the great "Remember" of the Jew, the prayer to God from the living.

The Christian funeral rite, as expressed in the Catholic tradition, is contained in the Catholic Burial Rite, which became mandatory on November 1, 1971, for all the Roman Catholic dioceses of the United States of America.[2]

According to McManus the funeral rite has several elements: ". . . a celebration of the paschal mystery of Christ, . . . the affirmation of Christian hope . . . a balance of older customs and new improved catechesis . . . the community's participation in the farewell to one of the brethern.[3] The author stresses:

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[1] Ibid., p. 79.

[2] The Catholic Burial Rite (Collegeville, Minnesota: The Liturgical Press, 1971), 3pp. 3-65.

[3] Frederick R. McManus, "The Reformed Funeral Rite - Part One," The American Ecclesiastical Review 166 (January 1972):46-47.

> Priests who prepare for funeral celebrations must consider the circumstances of the person and his family. This responsibility demands a direct, personal knowledge of the dead person who is to be honored and commended to God in the funeral rite. . . . The priest should listen to the wishes of the family and the community, take into account the diversity of circumstances, and employ the options granted in the rite. . . . Among other things, it is for the priest . . . to prepare with the family the appropriate celebration of the funeral, using the options suggested and granted in rite. . . .[1]

According to Kollar, the Catholic funeral rite must provide an opportunity for:

> . . . regeneration in which the deceased lives again in the memory of all present . . . identification in which the survivors recognize their share in the life of the deceased and their responsibility for guarding the values for which he lived, thereby immortalizing him.[2]

The author considers that these can best be experienced at the wake, where individuals are allowed to come to terms with death and its finality. He also proposes that the ritual should provide an opportunity for communal awareness which is created by the death of a member for confirmation of communal values, for the theme of the reality and the hope of the Resurrection of Jesus. He maintains that the church service should focus on the two principal themes of death and hope at the funeral of a Christian.

Article 82 of the Constitution on the Liturgy concerns itself with the funeral of children: "The rite for

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[1] Ibid., pp. 48-50.

[2] Nathan R. Kollar, Death and Other Living Things (Dayton, Ohio: Pflaum/Standard, 1973), p. 61.

the burial of infants is to be revised and a special mass for the occasion should be provided."[1] McManus comments on this: ". . . the intention was to replace the rite found in the old Roman ritual and the inappropriate custom in some places of celebrating the mass of the angels."[2]

The Catholic funeral rite has a threefold aspect: the wake service, service at the church and the cemetery service. It attempts to meet the needs of the mourner.

> A vigilant attempt has been made to so structure the rite that it moves toward a climax, from the vigil beginning with recognition of sorrow and loss, then to the meeting of the body at the door of the church reminiscent of the day of baptism, then to the eucharist liturgy to relate the eucharist to the death and life of the Christian, then to the final commendation as a fitting prelude to the procession from the church marking the triumph over death and finally to the ceremony at the cemetery at which the mourners look forward to final resurrection and parouisa.[3]

Whether the rite is celebrated in all its totality would ultimately depend on each funeral and the participants in it. Did that funeral meet the needs of the mourner? Geaney seems to indicate that the new Catholic funeral rite does not meet the needs of the mourner. He asks:

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[1] Austin Flannery, ed. Vatican Council II: The Conciliar and Post Conciliar Documents (Collegeville, Minnesota: The Liturgical Press, 1975), p. 24.

[2] McManus, "The Reformed Funeral Rite-Part One," p. 55.

[3] Theodore Stone and Anselm Cunningham, "The Chicago Experimental Funeral Rite," in Reforming the Rites of Death, ed., Johannes Wagner (New York: Paulist Press, 1968), p. 103.

> Is our liturgy for the deceased a form of inspirational repression? [This is defined as] . . . religious ways of bottling up our feelings of loss and blocking out the healthy sobbing that cleans out and purifies the tear ducts and gives us new energy.[1]

The author's question arose after he and a minister attended the funeral of a friend's father who lived a tragic life and died under tragic and embarrassing circumstances. After the funeral the author gives the following account of the minister's criticism:

> The homilist never alluded to the man's life. With a change of pronouns the homily could be used for any funeral. Was he sparing the family embarrassment or was he denying them the opportunity to recall memories no matter how painful?[2]

After writing about the change in the color of vestments from black to white, the dropping of the Dies Irae, the change from a sombre mood to a joyful one and the time demanded for grieving, Geaney asks questions very pertinent to the subject of this paper.

> Does our liturgy acknowledge where people are? Are we substituting the risen Christ when the mourners are still in the garden of Gethsemane with Jesus? Have American Catholics bought the American dream with its success model, sexist ads, and denial of old age, suffering and death? Are they denying the Resurrection in spite of the Alleluias and the white cloth on the casket?[3]

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[1] Dennis J. Geaney, "Give in to Grief," U. S. Catholic (February 1978):12.

[2] Ibid., p. 12.

[3] Ibid., p. 12.

The author does not answer the questions, but in the feedback section to the article there are some answers and additional questions from readers:

> It is necessary for our liturgy to move through the process of going from grief to glory. All we have now is the white vestments of glory. What would be wrong with wearing black vestments at the beginning of the liturgy while meeting the body and after communion putting on white vestments?[1]
>
> Have you ever laughed at a funeral? I've been to funerals where the celebrant has recalled a funny incident from the person's life to emphasize that he was the joyous one who would soon tire of our tears and long faces.[2]
>
> We've thought a lot about death since our daughter nearly died of cancer at age three. We had had to come to terms with some of our feelings about life and death--not an easy task.[3]

Another view is expressed by Fehren when he deals with a woman who was horrified that as the mother followed the coffin of her fifteen year old son out of the church she was singing. He told the woman, "the mother not only loved her son, but she had faith in him and she had faith in the promises of Jesus Christ."[4] He commented on the funeral liturgy in this context:

> The new funeral liturgy, in parishes loyal to the church and therefore receptive to its emphasis on the

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[1] Ibid., p. 14.

[2] Ibid., p. 15.

[3] Ibid., pp. 15-16.

[4] Henry Fehren, "Mother Sang at the Funeral," U. S. Catholic (January 1972), p. 41.

> Resurrection when a faithful follower of Christ dies, sings the belief and hope of the church. Many Catholics, at least those familiar with the New Testament (and the Old), are happy about the faithfulness of the new funeral liturgy to the teaching and promises of Christ. They are not cultic mashochists who prefer a Danse Macabre so that they can indulge in a self-gratifying orgasm of self-pity at someone else's death.[1]

The literature regarding the stages, phases and expressions of grief after death have been reviewed. The funeral process, the funeral of Keith, the one year old child with Down's syndrome, and the viewing of the body were also discussed. The Jewish and Catholic funeral rites were discussed, with particular reference to the latter's meaning and expression of the Resurrection of Jesus Christ.

The final phase of the after-death is the burial. The next section will concern itself with the cemetery, the grave and the family's final return home without their loved one.

Burial of the Person with Mental Retardation

> . . . Rob and Sue closed Keith's little casket and held it in their laps as about forty friends went with them to the cemetery. They wanted honesty and realism so the grave was not concealed by artificial grass and the pile of dirt was not hidden. Rob and Sue on their knees at the grave slowly, spontaneously, without any prior intent, placed Keith's body and casket into the grave and

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[1] Ibid., p. 41.

> carefully began to pull dirt into the grave. The astute minister only said, "I think the kids need some help." Forty friends passed along the dirt, handful by handful, with no shovels, until the grave was filled.[1]

Not all burials are performed in this manner. The general custom, in California, is for the casket to be placed on a platform over the grave. The grave and the dirt are usually concealed with artificial grass. After the commital service and when the family and friends have departed the casket containing the body of the deceased person is placed in the grave by the cemetery workers. They then fill the grave. In many parts of the country, due to lack of space, above ground burial in mausoleums is becoming more common. The grave is described by Gordon:

> The raw gaping hole in the earth, open to receive the coffin, is symbol of the raw emptiness of the mourner at this moment of final separation. Burying the dead by actually doing some of the shoveling themselves helps the mourners and the mourning community to ease the pain of parting by performing one last act of love and concern.[2]

Pantoga discusses many aspects of Catholic burial.[3] With regard to the question of where, the traditional

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[1] Nichols and Nichols, "Funerals," in Death; The Final Stage of Growth, ed. Kubler-Ross, p. 95.

[2] Audrey Gordon, "The Psychological Wisdom of the Law," in Jewish Reflections on Death, ed. Jack Riemer (New York: Jewish Publications, 1974), p. 100.

[3] Fritzie Pantoga, "A Down-to-Earth Guide to Catholic Burial," U. S. Catholic 43 (November 1977):16-21.

position of the church is that a Catholic be buried in a Catholic cemetery. However, there are mitigating circumstances and she quotes from the guidelines of the Archdiocese of Newark, New Jersey:

> Since Catholics have a right to a Christian burial in the cemetery of their choice, the priest must give it, including the station at the grave and its accompanying liturgical rites.[1]

She quotes the director of the cemetery:

> It makes not the slightest bit of difference to salvation whether you're buried in a Catholic cemetery or not . . . . The church takes the position that burial rites are meant to be consolation for the living.[2]

With regard to methods of disposal the author states: "Burial is the most common method. Burial practices have always been integrated with religious custom."[3] She points out, however, that the church has allowed cremation since 1963, and that if cremation does take place, the ashes are to be buried rather than scattered to the winds.

For a more detailed account of the funeral and burial, its costs and customs and the state of the funeral industry, the reader is referred to the works of Mitford[4] and of Irion.[5]

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[1] Ibid., p. 16.

[2] Ibid., p. 12.

[3] Ibid., p. 19.

[4] Jessica Mitford, The American Way of Death (New York: Fawcett, 1963).

[5] Paul E. Irion, The Funeral: Vestige or Value (Nashville, Tennessee: Arno Press, 1966).

Kollar sums up the burial service:

> It is especially at this point that they must let go of the dead, for here it is evident that they must go on living without this person, yet living in the light of the resurrection. With the burial, the living walk away. As the one who has died has changed, so have they. The living will never be the same. One is missing from their midst. But this is the fate of every man: to miss those we love; to feel the sting of death even while we live.[1]

When the burial has been completed there are different customs regarding what happens next. In the Jewish tradition:

> Returning from the cemetery the mourner finds a meal of recuperation waiting for him. This meal serves several purposes. It reassures the mourner that he is not alone and puts before the mourner the reality that life must go on.[2]

What about the person with mental retardation who has died? Do all the customs and religious rites apply in her or his case? The literature is silent. Can silence be construed as consent to a funeral service just like any other person who has died? It would seem so, if the preamble to the constitution of the National Apostolate for the Mentally Retarded, a predominantly Catholic organization, is to be taken seriously. It states:

> The mentally retarded are an integral part of society equal to other men, and persons possessing a fundamental value and dignity. They are recipients of

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[1] Kollar, <u>Death and Other Living Things</u>, p. 67.

[2] Gordon, "The Psychological Wisdom of the Law," in <u>Jewish Reflections on Death</u>, p. 100.

> what the church offers and contributors to it by virtue of their individual value and of the positive Christian attitudes they stimulate in others.[1]

This research paper began with the announcement by mothers of the death of their children with mental retardation. This chapter will end with similar accounts. One is from the postscript to a letter by McClinton. It reads:

> The above . . . was written in a hospital waiting room the morning of our little Mark's open-heart surgery. The operation was to correct a congenital heart defect (hole) that caused him much pain and early heart failure. Without the surgery he was given six months to two years to live, and we took the chance of his having a normal physical life. He was always but a step away from heaven. Even though he had come through the operation successfully, the shock was too much for his delicate make-up. He took his last heavenly step to our Lord's side on the morning of May 24, 1967.
>
> Our sorrow has been so great, but my heart knows why. Our Lord may have given little Mark to us because he loved little children so much that He wanted some of His creatures to remain as little children throughout their days, to give, in their innocence, delight to his loving heart. I believe Mark may have come to us because of prophetic words ". . . and a little child shall lead them." Because of Mark, the little child that led me, there is a Mothers Mutual to help parents of children comparable to him.[2]

Another is by Dale Evans Rogers:

> The two years of Robin's life were indeed blessed ones. She taught us true joy in the things that count and gratitude for those things.
>
> In 1952 shortly before she left us, I pleaded with the doctors to do heart surgery on her to correct the hole in her heart, but they said she couldn't stand surgery. Now I realize that Robin's mission was a short

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[1] National Apostolate for the Mentally Retarded, "Preamble to the Constitution," N A M R Quarterly 8 (Winter 1978):21.

[2] McClinton, Mothers Mutual Manual, p. 4.

> one, for God knew that I would never have written Angel Unaware as long as Robin was here.
>
> It is a balm to my heart to know that Robin's short life resulted in help for others like her and I am sure her little spirit glows more brightly each time Mothers Mutual visits the home of a new Angel Unaware.[1]

The final letter is a personal communication to the author from Trudy's mother. It says in part:

> I have found it difficult to let Trudy go. I know she is gone, but I talk to her almost every day. I guess I'm afraid to let her go because it would be like her never being here. I don't make much sense but I sure miss her. . . . Trudy's mass and burial were beautiful ceremonies. They touched many peoples' lives. Trudy was remarkable, because she touched people I didn't even know about. . . . The things to remember for the ritual for the final journey is A Personal touch and a Joyful mass. Some people told me it was hard for them to feel sad because you made it seem happy . . . . I don't know what we would have done without our faith. Thank God for it.[2]

Jewish and Catholic literature describing the burial of the person who has died has been reviewed. The question was raised whether the customs and beliefs described applied to the person with mental retardation. Accounts by three mothers concerning the lives, deaths, burials of and their remembrances about their children who had mental retardation were cited in this section.

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[1] Dale Evans Rogers, Foreword to Mothers Mutual Manual, by Helen A. McClinton (Colorado Springs, Colorado: El Paso Association for Retarded Children, 1967), p. 6.

[2] Irene Terusa, "Personal Letter," April 18, 1978.

Summary

This chapter has reviewed the literature concerning the birth of the child with mental retardation and the mourning, sorrow, death wishes and theological crisis experienced by the parents following the birth of a child with mental retardation. The coping mechanisms employed in pre-death and the stages and phases of grief at the death were reviewed. The funeral and burial were discussed. The following chapter will present a detailed summary and draw conclusions to assist the reader and the parents at the death and burial of a person with mental retardation.

CHAPTER III

SUMMARY AND CONCLUSIONS

Summary

The question was raised in the introduction to this research paper: What does the death and burial of the person with mental retardation really mean to the parents, friends and to the reader? This paper has attempted to answer that question.

The literature was reviewed and one reference was found to the actual death and burial of the person with mental retardation. Little was found on the parents' feelings and reactions to the death. However, much was written in the literature on the birth of the person with mental retardation and the effects on the parents. The question was raised: was there a connection?

The literature indicated that reactions by the parents to the birth of a child with mental retardation, such as mourning, chronic sorrow and death wishes were similar to those experienced at the death of a loved one. A counseling center reported that, after the birth of the child with mental retardation, they assisted the parents to cope. They instructed them about the basic psychological reactions to human trauma, reactions quite similar to those experienced by the terminally ill patient. The coping mechanisms employed at the time of a terminal illness were: denial and isolation; anger; bargaining; depression and acceptance. They did not indicate whether they instructed the parents about the phases of grief which a person experiences after the death of a loved one. These phases of grief in normal bereavement have a similarity, however, to the coping mechanisms of the terminally ill. They were proposed by one author as: shock and numbness; disbelief and illusions; a time of inner conflicts; the assumption of guilt; feelings of anger; aloneness; expressing of grief; acceptance and reintegration.

A review of reactions parents have, or the stages they go through, if any, following the birth of the child with mental retardation was attempted.

The fact that parents, following the birth of a child with mental retardation, go through different stages has been well documented in the literature. These stages, according to one author, were: the frantic searching for proof that the child is not handicapped; the crusade to prove that the diagnosis was wrong; and the final acceptance. According to another author, they were: the acceptance of the fact; the depletion of financial resources; the emotional build-up; the theological conflicts; the search for a solution; and the coping period. A third author described three stages that a parent goes through which were: the involvement with the self; the involvement with the child; and, finally, the involvement with others.

The literature dealt with the concept of acceptance and with its opposite, rejection, in relationship to the parents' feelings about their child with mental retardation. Factors such as the parents' position on the socio-economic ladder, the severity of the retardation and child-care problems were suggested as variables which affect the acceptance or rejection by the parents of the child with mental retardation. Other factors, such as age, sex, etiology, and social and religious background were also proposed as having an influence on the parental acceptance or rejection. Four general areas where parental rejection can be expressed were presented by one author. They were: strong underexpectation of achievement; goals being set too high; escape in the form of abandonment or placing the child at a distance; and reaction formation. What a child means and how parents see and understand their child with mental retardation were considered by some authors as being very important in acceptance. The following were considered important factors in the development of the parents' viewpoint: the parent views the child as a physical and psychological extension of the self; the child is a means of vicarious satisfaction to the parents; the parents can transcend death through their child; the child is seen as a personalized love object; the parent has feelings of worth in meeting the dependency needs of the child; the parents may have negative feelings about the limitations and demands of child-rearing. The part that guilt plays in acceptance was studied by one author who suggested that Catholic mothers were more accepting of their children with mental retardation than were other mothers. He proposed that this was due to the fact that Catholic doctrine provides considerable emotional support for mothers by its insistence that every child, normal or defective, is a special gift from God bestowed on parents.

In the literature, two authors proposed that the birth of a child with mental retardation was a severe narcissistic blow to the parents, similar to the loss suffered through the death of a loved one, leaving the parents in a state of acute grief. They hypothesized that, since the mother expects a "perfect child," the birth of the defective child means the loss of the normal child. The mother goes through a mourning process for the perfect child prior to the acceptance of the child with retardation.

Another author disagreed and proposed instead that the parents who have a child with mental retardation suffer "chronic sorrow" throughout their lives. This chronic sorrow varies in intensity according to circumstances and time.

A number of authors suggested that the concern for, or the effect of, the birth of the child with mental retardation was often expressed in death wishes. While these aroused guilt feelings in the parents they were not to be considered as alarming or indications of neurosis. The authors stated that these death wishes were often denied, pushed back, and could cause real problems in the parents' relationship with the person who has mental retardation.

The review of the literature also indicated that the birth of a child with mental retardation caused a theological crisis in the personal lives of many parents. One author proposed that any condition of life which destroys or permanently damages a person's concept of a loving and merciful God presents a serious conflict of faith. The birth of a child with mental retardation was seen as such a condition. Another author suggested that, not only does the birth of a child with mental retardation affect the religious faith of the parents, but that religious faith also affects the parents' response to this event. Another author proposed that religious faith could be affected positively or negatively. The author stated that faith had three factors as formative influences, namely: the religious affiliation of the parents; the religious interpretation of the cause of the illness; and the religious teaching regarding the expression of feelings. Another author, a parent of a child with mental retardation, equated the positive theological crisis effected by the birth of the child with mental retardation, and the third stage of growth, the involvement of the parents of the child with mental retardation with other parents.

This paper did not review the critical periods in the growing-up years, the school years, where many persons with mental retardation and their parents strive toward meeting their full potential in joy and sorrow. It recognized however that these experiences were very important, especially in light of the original question of the meaning of the death of the person with mental retardation, who had a name, a unique personality and unique life experiences.

The experience identified as pre-death was described as found in the literature. One author felt that mourning was less intense if prepared for during the slow process of death from chronic illness. This preparation was termed "anticipatory mourning." One author defined it as a set of processes related to the awareness of the impending loss and the adaptive mechanisms whereby emotional attachment to the dying person is relinquished over time. These processes were: acknowledgement; grieving; reconciliation; detachment; and memorialization. Other authors reported on the process of anticipatory mourning of parents of a child with leukemia. These parents went from a purely intellectual to an emotional acceptance of the fatal nature of the child's disease. After a period of grief there was a gradual detachment of investment from the child, leading to a philosophical resignation which enabled the parents to be better prepared for the eventual death. Sadness, anger and reinvestment were proposed as elements of anticipatory mourning by another author. The same author pointed out that if the child was very young or was sick from birth, or repeated illness kept him or her away from home, the parents may have long before separated emotionally even though s/he was now dying.

Another author indicated that the mourning process begins with the pronouncement of the diagnosis of the fatal disease. This viewpoint reflected that of others cited in this paper who indicated that the parents go through a mourning process at the announcement that their child has mental retardation. The problem presented to the treatment team who have to deal with the dying children and the mourning family, where the family successfully completes the mourning and reinvests elsewhere before the child is actually dead, was discussed by one author.

Another phenomenon in pre-death was "maintenance of confidence" which was defined by some authors as the set of processes that facilitates parents' sense of worth, trust and mastery in the face of potential guilt, rage and helplessness. The processes were: mastery operation such as search and participation in care; maintenance of equilibrium;

affirmation of life; and re-organization. They concluded that those parents who were able to accomplish the task of anticipatory mourning were also able to maintain confidence during the child's illness and after death.

The questions of whether to perform surgery or whether the person should be allowed to live or die were reviewed as they relate to the child or person who had multiple defects or complications at birth or later in life. The literature indicated that the parents were the final decision-makers. One author devoted a book to the subject outlining the quality of life basis for the decision and the sanctity of life position. He proposed that every handicapped child should be treated unless the treatment is not likely to be successful or would impose an excessive burden on the child and family.

The literature indicated that the child with mental retardation should receive the sacrament of the anointing of the sick.

Prevalent attitudes towards death were described as: nothingness; non-being; man's greatest mystery and source of fear; a destroyer and a redeemer; the ultimate cruelty; the essence of release; a part of each person's life; an atonement for sins and errors; an event concerning man as a whole; a consequence of sin; a dying with Christ; the beginning of eternity; an opportunity for man to pose his first completely personal act; the moment for the encounter with God; the hypothesis of the final decision; a full encounter with self; the final stage of growth.

A possible partial answer to the question of the meaning of the death of the child with mental retardation was given by two authors. They proposed, in different ways, that infants in death enter into the full possession of their spirituality. They are able to make their final decision in full liberty and knowledge at the moment of death.

Different but similar stages, phases and expressions of grief after death were presented by different authors. They were: a stage of shock and denial; anger; bargaining; a prolonged state of depression; acceptance; a phase of shock and numbness; disbelief and illusions; a time of inner conflict; the assumption of guilt; feeling of anger; aloneness; expressing of grief acceptance and reintegration; waves of somatic distress; a tightness in the throat; frequent crying and sighing; a feeling of emptiness; fatigue and lack of appetite; a preoccupation with death and the deceased; a distance from and a loss of warmth for other people; much talking about the deceased; a realization that a large part of the person's customary activity was done in some meaningful relationship to the deceased and now has lost its significance.

One author outlined the segments of the funeralization process: the initial notification of death; the counseling session with the funeral director; the community notification of death; the public visitation and viewing of the body; the church service; the processional to the final place of disposition; the committal service activities.

The death and burial of a one year old child with Down's syndrome was described in detail. The feelings and experiences of the parents reflected those described by many authors in the preceding part of this paper. The parents decided to unload their pain fast and hard and participated fully in the funeral and burial.

Different viewpoints were presented in the literature regarding the viewing of the body of the person who has died. One author felt that it was unnecessary especially after a prolonged illness. Another felt that it did not contribute in any way to grief therapy, and stated that North America was the only place the custom was tolerated. Another author felt that if it was omitted it could be one of the most damaging aspects of the funeralization process.

The Jewish funeral rite as presented in the literature was discussed. There are two distinct and separated phases in the process of mourning for the Jewish people. They are the Ainut, which represents the spontaneous human reaction to death and the Avelut, which is the picking-up of the debris of the mourner's shattered personality and re-establishing himself or herself as man or woman, restoring lost glory, dignity and uniqueness. The point where one is transformed into the other is to be found in the recital at the grave of the Kaddish, the great remembrance prayer of the Jew.

The Catholic funeral rite includes; the celebration of the paschal mystery of Christ; the affirmation of Christian hope; the community's participation in the farewell to one of the brethern; a balance of older custom and new improved catechesis. One author proposed that it must provide an opportunity for regeneration, identification, communal awareness, confirmation of communal values, the theme of the reality of death, and the hope of the resurrection being proclaimed by the Christian. The Catholic rite has a threefold aspect: the wake service; service at the church; and the cemetery service. Whether the Catholic funeral rite meets the needs of the mourner was discussed. One author questioned whether or not it was a form of inspirational repression, or a denial of the Resurrection in spite of the Alleluias and the white cloth on the casket. Another author felt that it does meet the needs of the mourner, and sings the belief and hope of the church.

The final stage of the funeral process, the burial, was reviewed. The open grave was presented by one author as the symbol of the raw emptiness of the mourner at the moment of final separation. The filling of the grave was seen as helping the mourners to ease the pain of parting by performing one last act of love and concern. One author summed up the burial when he stated that with the burial the living walk away, changed and with one missing from their midst. They must go on living without this person, yet living in light of the resurrection.

Where the Catholic was to be buried was discussed. The conclusion that it made not the slightest bit of difference to salvation whether the person was buried in a Catholic cemetery or not was presented.

To the question of whether these customs and rites applied to the person with mental retardation, the silence in the literature was construed as saying yes, they did. This was asserted with confidence in light of the statement contained in the preamble to the constitution of a Catholic organization. It stated that the person with mental retardation was an integral part of society, equal to other men and a person possessing a fundamental value and dignity.

Three letters of mothers of children with retardation describing what their children's lives and deaths meant to them were cited. The mothers expressed sorrow at the loss, saw meaning in their children's lives and two of them had come to the stage of acceptance and involvement with the parents of other children with mental retardation. One mother, whose daughter's death was recent, was still in the process of letting go, and expressed thanks to God for her faith which brought her through. She recommended that the things to remember for the ritual of the final journey were a personal touch and a joyful mass.

This paper has examined the total life-span of the person with mental retardation in an attempt to answer the question: What is the meaning of the death and burial of the person with mental retardation? It has gone in a circle, from death to birth to death to burial, and therein may lie the answer for:

> Death belongs to life as birth does. The walk is in the raising of the foot as in the laying it down.
>
> Rabindranath Tagore
> "Stray Birds"[1]

Conclusions

The picture presented by a review of the literature regarding the death and burial of the person with mental retardation would seem to be best described and summed up by the statement that the parents have been there before. The experiences, reactions and expressions of sorrow, normally present at the death of a family member, were experienced by the parents before; either following the birth, at the announcement of the diagnosis of mental retardation or at the period of pre-death. Parents have probably experienced mourning, shock, grief and aloneness and have gone through

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[1] Rabindranath Tagore, Stray Birds (New York: Macmillan Publishing Co., 1916), p. 76.

the stages of coping, many months or years before the death and burial of the person with mental retardation. They all have had different experiences, therefore the state of acceptance at the death will also be different. How they have coped with the experiences brought on by the birth and the life of the person with mental retardation will be different according to the uniqueness and individuality of each parent and family.

From the reports in the literature it may be concluded that Catholic mothers, who were described as more accepting of their child with mental retardation, may also be more accepting of the death of their child.

If the parents expected and longed for the birth of the "perfect child" and had envisioned the birth of the handicapped child as being equal to the death of the normal child, they may have had death wishes toward the handicapped child. Since it had not been socially acceptable to express these wishes publicly while the person with mental retardation was alive, they may express satisfaction when the person dies. The expressions, "Thank God s/he has died," or "S/he won't have to suffer any more," or "S/he is better off," are often used. However, because of reaction formation or because these feelings are not fully socially acceptable, the parents may subdue them. To assist the parents in this area the author of this paper, after the death of the person with mental retardation, offered congratulations to the parents on the fact that their son or daughter was now a saint with God in heaven. This approach gave the parents an acceptable way to express relief, such as, "Thank God my son/daughter is safe with God." (Also meaning, "Thank God my son/daughter is dead and the ordeal is over.") Both of these expressions are healthy; they assist the parents in letting-go and speed the process of readjustment.

During the pre-death phase the pastor and others should assist the parents and the person with mental retardation to prepare for the final journey. Whenever possible the author of this paper celebrated the administration of the Sacrament of the Sick to the ill person. He attempted to do this especially when the parents were present and also conferred other sacraments such as Baptism, Confirmation and Holy Eucharist, when needed. He strongly recommends that the parents, friends and the clergy pray with the person with mental retardation when possible, and speak in simple and joyful words about his/her final stage of growth with Jesus and Father God. In the author's experience, many persons with mental retardation have an understanding of death that is quite accepting and joyful. Further research of vital importance could identify the feelings and understanding of persons with mental retardation toward death and the methods and means of preparing them for their final stage of growth.

Because many of the parents may have experienced a theological crisis following the birth of their child with mental retardation it would seem that the death would also have a similar affect. This crisis may also be joined with feelings of guilt or shame which could be expressed in wanting to do for the person who has died what they could not do for him or her in life. Examples of this may be the requesting of an elaborate and very expensive funeral or the opposite, no funeral, because they were ashamed of him or her in life, and have similar feelings in death. The astute pastor will attempt to determine where the parents are and assist them in their faith expression of the death of the person with mental retardation.

The funeral can be a time for catharsis, for the bringing of many past and present feelings to a point of understanding, completion and fulfillment and especially for a resolution of the theological crisis.

Because many parents have experienced the pre-death process known as anticipatory mourning they may, at the death itself, have been there "twice before" and therefore may be all "mourned-out." They may be ready to celebrate the final decision with a "joyful Mass."

Because many parents described in the literature experience maintenance of confidence problems, such as establishing a sense of self-worth, the author has read or has sung the poem "Heaven's Very Special Child" as contained in Appendix B, after the Communion at the Mass or as the opening hymn at the graveside service.

The meaning of death will be different for each person and family. From a review of the literature this author concludes that the definition of death that best describes the experience of life and death of the person with mental retardation is that of the final decision, the final encounter with self, the victory in Christ, the final stage of growth.

The person with mental retardation who has died should have a funeral like his fellow Christians, his fellow Jews, and his fellow persons. They are equals of other men and women, created in the image of God and this dignity that is theirs should be celebrated fully in the context of their particular religious tradition.

The author of this paper has participated in many funerals of persons who were handicapped with mental retardation. He fully agrees and supports the recommendations by Trudy's mother that the main elements of the ritual of the final journey should include a personal touch and a joyful Mass. To develop the personal touch it is strongly recommended that the priest and the parents plan the funeral service together. The author has found that parents can contribute in a very meaningful way in this endeavor. The author has also found that parents prefer either a simple but meaningful graveside service or an evening Mass in the church with a quiet graveside service the following morning. The casket would be open in the church during the Mass for the final farewell by the community.

The manner of the funeral and burial of Keith is recommended if the parents want to unload grief hard and fast. At least parents should not be rushed and should have time alone with the body of their son or daughter. They have been there before and can now deal with death and let go.

Outlines of the funeral liturgies for Dottie and Brian are included in Appendix C. The author had the privilege of celebrating the Mass of the Resurrection at both of them.

At Trudy's evening funeral Mass of the Resurrection her body was welcomed into the church with the song "You Great Big Beautiful Doll." This was the song that her mother sang to her during her life in joy and sorrow. A large congregation was led in the singing by Trudy's sisters and brothers. Poems and scripture readings were read by members of her family. The homily was given from a position beside the open casket. It combined the facts and meaning of her life with the joyful reality of her position with God for all eternity. This point was deeply emphasized and celebrated. The gifts of bread and wine for the Eucharist were presented by the parents who had given Trudy the original gift of life and the stepping stone to final growth. The Eucharist was shared in recognition of the need for the life-giving bread of the Lord, to assist us all in carrying on. Afterwards the poem "Heaven's Very Special Child" was recited. The time for the final goodbye was drawing close and the author of this paper spoke on behalf of Trudy the words of the "Beatitudes of the Handicapped" adapted as a "Thank You From a Friend." It is contained in Appendix D.

That evening the family continued the celebration of the final victory with God of one of their own. Neighbors, friends and relatives gathered at their home to share food, refreshments, friendship and memories.

The following morning the family said their last goodbyes to the body of Trudy and with the singing of the Alleluia the author of this paper took the cross from the closed casket and presented it to the parents. He reminded them that the death of Jesus on the cross was followed later by His Resurrection and so the cross taken from the casket was given to them as a crown, a sign of victory, a symbol of hope in the resurrection of all, because of the Resurrection of Jesus. It was to symbol Trudy's life which combined sorrow and joy for all concerned and now had reached its final glory. A flower, taken from the bouquet on the casket, was presented to each of the family members with the message to carry on in faith and joy toward the time of their "stage of final growth." All of this was done keeping in mind the words of St. Paul:

> This corruptible body must be clothed with incorruptibility and the mortal immortality, then will the saying of scripture be fulfilled: "Death is swallowed up in victory. O Death, where is your victory? O Death, where is your sting?" The sting of death is sin and sin gets its power from the law. But thanks to God who has given us the victory through Our Lord Jesus Christ.[1]

He says further:

> Indeed we know that when the earthly tent in which we dwell is destroyed we have a dwelling in the heavens not made by hands but to last forever . . . . God has fashioned us for this very thing and has given us the Spirit as a pledge of it.[2]

Thus what does the death and burial of the person with mental retardation really mean? To the person, we don't really know since he or she has not returned from the encounter with the self and with God to inform us. To the parents, this is the second time around for many of them, they are feeling sorrow at the loss. To all of us the death reflects the life which had meaning and now is expressed in the hope of the Resurrection of Jesus.

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[1] Cor. 15:53-57 (NAB).

[2] Cor. 5:1-5 (NAB).

This paper has reviewed the literature regarding the death and burial of the person with mental retardation and the affects on the parents. Would the parents themselves agree with the descriptions of feelings found in the literature? This paper calls for further survey research into the experiences and feelings of parents, especially parents of persons with profound, severe or moderate retardation. A special effort should be made to study the feelings and experiences of parents of persons with mental retardation who have died.

The closing remark by the Wiggins family at the funeral liturgy of their daughter Dottie contained in Appendix C may possibly sum up the meaning of the life, death and burial of the person with mental retardation for many parents:

> If any one of us could bring as much love into the world in one year of our lives as these children bring in one day, oh what beautiful families, countries, world this would be.

Thus for the author, the meaning of the death and burial of the person with mental retardation is that it creates great sorrow, for a friend has departed us, but ultimately it generates great joy for a fellow traveler has made the final decision, has had the ultimate encounter with the self. This self we barely understood for it reflected not a drive for social consciousness, but a capacity for love that was immediate, simple and full.

The self reflected the immense qualities of the heart as distinct from those of the mind. That reflection may often have been ignored by us. This self, at the level of grace and faith, challenged us and forced us to open our eyes and minds to look beyond. This unique self, expressed in all that he or she was and did through life and in death, gave us a glimpse of the strength and fraility of the human family. He or she stimulated believer and non-believer alike to a renewed appreciation for the words of the Psalmist:

> Sing joyfully to the Lord, all you lands;
> serve the Lord with gladness;
> come before him with joyful song.
> Know that the Lord is God;
> He made us, His we are;
> His people, the flock he tends.
> Enter his gates with thanksgiving,
> His courts with praise;
> Give thanks to Him, bless His name,
> for He is good:
> the Lord, whose kindness endures forever,
> and His faithfulness, to all generations.
>
> Psalm 100.[1]

The person with mental retardation who has died joins equally with all the people who have gone before, who have made their final decision, and reached their final stage of growth. The parents, even though they have been there before, join all parents the world over in the feelings expressed in the following poem by Edgar A. Guest addressed "To All Parents":

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[1] Psalm 100. The Book of Psalms (NAB).

"I'll lend you for a little time a child of mine,"
He said.
"For you to love the while she lives and mourn for
when she's dead.
It may be six or seven years or twenty-two or three
But will you, till I call her back, take care of her
for Me?
She'll bring her charms to gladden you, and should her
stay be brief
You'll have her lovely memories as solace for your grief.

I cannot promise she will stay, since all from earth
return,
But there are lessons taught down there I want this
child to learn.
I've looked the wide world over in My search for teachers
true
And from the throngs that crowd life's lanes I have
selected you.
Now will you give her all your love, nor think the
labor vain,
Nor hate Me when I come to call to take her back
again?

I fancied that I heard them say, "Dear Lord, They
will be done!
For all the joy Thy child shall bring, the risk of
grief we'll run.
We'll shelter her with tenderness, we'll love her
while we may,
And for the happiness we've known forever grateful stay;
But should the angels call her much sooner than we've
planned,
We'll brave the bitter grief that comes and try to
understand.

Edgar A. Guest
"To All Parents"[1]

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[1] Edgar A. Guest, "To All Parents," All in a Lifetime (Chicago: The Reilly and Lee Co., 1938), p. 18.

APPENDIX A

Pacific State Hospital and Developmental Center

Administrative Directive

DEATH OF RESIDENT/PATIENT

Pacific State Hospital and Developmental Center

ADMINISTRATIVE DIRECTIVE

Number: RESIDENT CARE 1

Date: 3 November 1977

Harry A. Lewis
Executive Director

Subject: DEATH OF RESIDENT/PATIENT

I. GENERAL

Although overall responsibility for carrying out treatment/habilitation programs rests with the Program Directors, it is understood that the physicians and social workers have responsibility for carrying out death procedures. Therefore, this Directive and its supplement refer to the responsibilities of the staff in the event of a resident/patient's death. It is expected that in addition to the physician's and social worker's necessary involvement, the Program Director will be in close communication with the family during this time of emotional stress.

II. POLICY

Department of Health policy requires that the Coroner be notified of all deaths occurring at State hospitals. All deaths shall be reported to the next of kin by the hospital physician immediately following notification of the Coroner's office.

Every member of the medical staff is expected to be actively interested in securing an autopsy. No autopsy shall be performed without proper written consent. All autopsies shall be performed by the hospital pathologist, by another physician designated by the Chief of the Medical Staff, or by the Coroner.

All contact and correspondence with relatives or guardians shall be handled in a manner most considerate of the feelings of all concerned.

III. PROCEDURES

A. When death occurs, staff in attendance or staff discovering the death shall immediately notify the telephone operator and request the services of a physician and a hospital peace officer. The telephone operator will immediately make the following notifications:

1.	Protective Services Office	Extension 400
2.	Program Director - Program 1	Extention 383, 510
	Program 2	Extension 230
	Program 3	Extension 239
	Program 4	Extension 490
	Program 5	Extension 498
	Program 6	Extension 573
	Program 7	Extension 590
	Program 8	Extension 268, 217
	Program 9	Extension 268, 491
3.	Hospital Special Investigator	Extension 295
4.	Administrative Assistant	Extension 325
5.	Chaplain	

a. Catholic - When a Catholic **patient** dies suddenly, notify the Catholic Chaplain immediately, day or night, Ext. 251, or through the switchboard.

b. Protestant - When a Protestant patient dies, notify the Protestant Chaplain, Ext. 352, or through the switchboard during the duty day, or the morning following, in case the resident expires at night. If the family wishes the presence of the Protestant Chaplain, he may be called at any time.

c. Jewish - The Rabbi is to be notified through the switchboard.

If a death occurs after hours or on a weekend or holiday:

1. The Telephone Operator, Protective Services Office, the Program Director and the Executive Officer of the Day are notified immediately.

2. The Program Director will notify the Administrative Assistant by 0900 hours on the next regular working day and provide sufficient information to alert headquarters.

3. The Administrative Assistant will alert headquarters by telephone during regular business hours.

B. A log which will form the basis for the Special Incident Report will be started by ward staff which will indicate the time, place and circumstances of the death, the time of the request for the Physician and Hospital Peace Officer and all subsequent activity until removal of the deceased from the ward. (See sample of Form NOD 1036 attached).

C. The Coroner will be notified by the attending Physician in each case of death, whether natural or otherwise. (See Resident Care 1, Supp. A).

D. The attending Physician will evaluate the circumstances and cause of death to the degree possible and will report findings for the record.

E. The Hospital Peace Officer will, upon arrival, take possession of the medical record of the deceased and will also make Polaroid photographs for the record. Sufficient photographs shall be taken to document thoroughly the condition of the deceased and the immediately surrounding area.

F. The body shall not be moved, nor the area around the body disturbed, except as necessary for lifesaving purposes until authorized by the Coroner. Should the Coroner be unable or unwilling to respond in a reasonable period of time, the Chief of Medical Staff or his Physician alternate, on advice of the attending Physician and the Hospital Peace Officer may authorize removal of the body.

G. The Hospital Peace Officer will make necessary elements of the medical record available to the Coroner (See W&I Code Section 5328. 4). The elements made available must be limited solely to information relating directly to the factual circumstances of the death and may not include information relating to the patient's mental state, circumstances of admission, or treatment. Should the Coroner require parts of the record for his file, the Hospital Peace Officer will immediately arrange duplication so the complete file can remain at the hospital. The record will then be placed on file in the Special Investigator's office where it will be made available to persons authorized by the

Executive Director. Any necessary additions to the record will be made under the supervision of the Hospital Peace Officer and identified as being made post-death.

H. The Program Director shall prepare the Special Incident Report, Form 1766-A within 24 hours (excluding weekends and holidays) and forward it to the office of the Executive Director via the Administrative Assistant. The report must be submitted by 1530 hours in order to be included in the Headquarters mail for that business day.

IV. COMMUNICATIONS WITH THE FAMILY

A. Responsibilities of the Physician

With every effort at sensitivity to the feelings of the persons being notified. since any indication of lack of concern or harsh attitude would not only increase the emotional trauma for the family but might also be magnified into a serious public relations problem, the physician will:

1. When the responsible relative, guardian or conservator is present at the time of death:

    a. Request permission to perform an autopsy and have the person sign the Autopsy Consent Form (Form DOH 1752) in duplicate if permission is granted. Note: It is hospital policy for both parents to sign the permit unless only one has legal custody. If necessary, obtain the permission of a parent not present by procedures outlined below. It should be noted that autopsies are not generally performed on weekends or holidays because the pathologist is not available.

2. When the responsible relative, guardian or conservator is not present:

    a. Immediately after the resident has been pronounced dead, notify the responsible relative or guardian by phone as gently as possible and obtain the following:

        (1) Ascertain if they wish to view the body. Hospital policy is to leave the body on the Unit/Ward a reasonable time if the family indicates a desire to view the body.

        (2) Monitored oral permission to perform an autopsy. The responsible relative must then confirm by a collect telegram to the hospital. Autopsies are not ordinarily conducted on weekends or holidays. The permission is to read as follows:

> "We/I, the parents or guardian, give permission to the Medical Staff of Pacific State Hospital and Developmental Center, to perform a complete post mortem examination including the retention of tissues deemed necessary by the pathologist on (Name of Deceased) ."
>
> Signed by both parents or the one who is the legal guardian, or other person who is the legal guardian.

"Nosotros/Yo, los padres o guardianes, damos el permiso al grupo medical de Pacific State Hospital para ejecutar un escaminacion completo de autopsia, incluyendo la conservacion de tisu juzgado necesario por el medico patalogo sobre (Nombre de defunto) ."

Firmado por los dos padres o el padre que el guardino legal o otra persona que sea el guardiano legal.

b. Request the hospital telephone operator to send the following prepaid telegram to the responsible relative, guardian or conservator confirming the telephone conservation (every effort should be made to use the language of the parent).

"This is to confirm our telephone conversation of (last night, today, etc.). We regret to report (resident's name) passed away (yesterday, today, etc.)

Harry A. Lewis, Executive Director
by (physician's name) "

"Esto es para confirmar la conversacion por telefano de (anoche, hoy, ayer, ecc.) . Sentimos de informar que (Nombre de residente) fallecio (hoy, ayer, ecc.).

Harry A. Lewis, Director Executivo
Por (Nombre del Medico) "

c. When all attempts to contact the responsible relative, guardian or conservator by phone have failed, the attending physician should notify them by means of a telegram sent to the home, with instructions to Western Union to notify the hospital if and why the telegram could not be delivered.

d. If there are no known surviving relatives and no guardian or conservator, or their whereabouts are unknown, contact the Social Worker during office hours. It is possible to secure permission for an autopsy from the Curator of Unclaimed Bodies, Office of Unclaimed Bodies, 213/226-2279 after the case is released by the Public Administrator, 213/974-0460.

B. Responsibilities of Other Hospital Staff

1. The Social Worker or Unit Charge will ask the relative or guardian what they wish to do with the personal effects of the deceased. If the person so desires, these can be donated to the hospital. A statement to this effect should be signed by the responsible relative or guardian.

2. The Social Worker will notify the appropriate Regional Center.

3. The Social Worker will discuss arrangements for disposition of the body. The family of the deceased is directly responsible for making funeral and burial arrangements and for paying the costs incurred therewith. The family is asked to notify the hospital of the mortuary chosen.

a. If the next of kin does not live in California, permission to release the body must be obtained from the Public Administrator, 213/974-0411, before the mortuary can pick up the body.

b. If the family or next of kin can assume only partial financial responsibilities, or state that they are unable to pay the burial expenses, assist as follows:

(1) Contact the Trust Office to find out if the deceased person has funds in his account which may be used to defer some or all of the expenses (in an amount not to exceed $500 per W&I Code Section 7281). The mortuary may then send a bill to the hospital for the amount available in the account.

(2) If the resident is of the Jewish faith, call the Rabbi at Ext. 329 or 213/469-5391 and he will make the necessary arrangements. If for any reason the Rabbi cannot be contacted, telephone 213/852-1234 and ask for either Mrs. Dorene Agin of the Jewish Family Service or Rabbi Harry Hyman of the Board of Rabbis of Southern California. If none of the above is available, Groman Mortuaries in Los Angeles may be called as a last resort. NOTE: If the body was unclaimed, release must first be obtained from the Public Administrator's Office, phone 213/974-0411.

(3) County burial may be arranged as follows:

(a) If next of kin lives in California, call the Los Angeles County Mortuary at 1200 North State Street, Los Angeles, California 90033, telephone 213/226-7161, giving them brief information such as name, location of body, family's inability to pay, etc. The family must then sign a statement (or send a telegram to the Los Angeles County Mortuary) verifying their inability to bury the individual because of lack of funds and authorizing the mortuary to dispose of the remains.

"We (names), parents are without funds to bury (name of resident), our (son, daughter, etc.) and hereby request the Los Angeles County Mortuary to dispose of his/her remains by means of a (Catholic/Protestant) burial/cremation."

(b) If next of kin does not live in California, call 213/974-0411, the Public Administrator in Los Angeles. After obtaining his/her permission, contact the Los Angeles County Mortuary, 213/226-7171 to arrange for burial of the deceased.

c. If attempts to locate any next of kin are unsuccessful, follow the procedures outlined above in Section IV.B.3.b(2) if the deceased was of the Jewish faith. For all others, call the Public Administrator's Office, 213/974-0411 and ask them to accept responsibility for the case. Information required:

(1) Father's and mother's (maiden) full name, their birthdates, their birthplace and social security numbers.

(2) Resident's date of birth, birthplace, religion, date of admission to this hospital, date, time, cause and place of death.

If the Public Administrator accepts the case, call the Los Angeles County Mortuary, 213/226-7161 and inform them that the case has been accepted by the Public Administrator's office and of the time at which they may pick up the body. Information required.

(1) Father's and mother's (maiden) full name, their birthdates, their birthplace and social security numbers.

(2) Resident's date of birth, birthplace, religion, date of admission to Pacific State Hospital; date, time, cause and place of death.

4. The Medical Records clerk will complete the death certificates and notify the mortuary when the body can be released.

V. RECORDING PROCEDURES

A. Report of Death, Form NOD 1087 MR (in duplicate) completed on Ward/Unit.

1. Original filed in deceased's record.

2. Carbon copy is sent to the Executive Director.

B. Forms required if an autopsy is performed:

1. Authority for Autopsy, Form DOH 1752, in duplicate
OR
Telegram giving consent for autopsy (make photocopy for duplicate)

a. Original is filed in deceased's record, Section V
b. Copy to Pathologist

2. Post Mortem Examination Report, Form MR 1167 MR, in duplicate, is initiated by Medical Records and completed immediately following the autopsy by the Pathologist. When a necropsy is performed, provisional anatomic diagnoses should be recorded within 3 days (72 hours).

a. Original is filed in deceased's record
b. Copy to Pathologist

3. Autopsy Report Protocol, , Form 1711 A is completed by the Pathologist within three months and filed in the deceased's record.

C. Certificate of Death, Form R&S 11 (in triplicate)

The Medical-Surgical Medical Record Office staff will complete the form on all death cases, including Coroner's cases, during regular working hours. In the few cases when the certificate must be completed before the next regular working day, the Program 1 Nursing Coordinator will complete the certificate.

1. The physician, <u>except in Coroner's cases</u>, will:
    a. Provide the cause of death (using ICDA medical terminology) and approximate interval between onset and death.

    b. Sign the certificate with black ink.

2. Distribution of three copies:
    a. Original is sent with the body.

    b. First carbon copy is filed in the deceased's record.

    c. Second carbon copy is routed to Medical Records and Data Processing for statistical use.

D. <u>Receipt for Body</u>, Form MR 1085 MR (original only)

This receipt is signed by the person picking up the body. The form, which is filed in the deceased's record, is available either from the Medical Record Department, Nursing O.D. or Telephone Office.

In Coroner's cases, if the body is picked up by a mortuary, the person should note that he is picking up the body for the Coroner.

E. The physician shall record all deaths in the Medical Officer of the Day book. The Nursing OD Office will record in the acute NOD and residential NOD office log book, as appropriate, on all deaths.

F. <u>Release Summary</u>

If death occurs when a resident has been a patient in the Acute Unit for less than 48 hours, the summary is written by the physician assigned to the deceased's residential unit. In all other cases, the summary is written by the physician assigned to the ward/unit where the death occurred.

When an autopsy is granted, this summary must be dictated in sufficient time to be typed before the post mortem examination.

G. <u>Headquarters Reportable Incident</u>, Form MH 1766 B

The Program Director prepares this form and submits it to the Executive Director, via the Administrative Assistant, within 24 hours of the time of death.

APPROVED FOR THE GOVERNING BODY:

Harry Lewis

Harry A. Lewis, Executive Director

APPROVED BY THE MEDICAL STAFF:

Frederick Martin M.D.

Frederick Martin, M.D.
Chief of the Medical Staff

HAL:KH:MP:RH:MS:VS:hb
DISTRIBUTION: Standard
Please remove and discard Administrative Directive Resident Care 1 dated 7/20/76 and Hospital Bulletin Number 76-10-14 dated 10/15/76.

APPENDIX B

POEM

"Heaven's Very Special Child"

Heaven's Very Special Child

A meeting was held quite far from earth.
"It's time again for another birth,"
Said the Angels to the Lord above,
"This special child will need much love.

"His progress may seem very slow,
Accomplishments he may not show,
And he'll require extra care
From the folks he meets way down there.

"He may not run or laugh or play,
His thoughts may seem quite far away.
In many ways he won't adapt,
And he'll be known as handicapped.

"So let's be careful where he's sent.
We want his life to be content.
Please, Lord, find the parents who
Will do a special job for You.

"They will not realize right away
The leading role they're asked to play.
But with this child sent from above.
Comes stronger faith and richer love.

"And soon they'll know the privilege given
In caring for this gift from Heaven.
Their precious charge, so meek and mild,
Is Heaven's very special child!"

-Anonymous

APPENDIX C

FUNERAL LITURGIES

DOTTIE WIGGINS

June 4, 1964 -- February 23, 1976

A DOUBLE BLESSING

A blessing that she returned to her heavenly Father--Yes indeed--A double blessing that she lived, laughed, and walking among us, charmed us all with her love.

A JOYFUL EUCHARISTIC CELEBRATION OF LIFE - ETERNAL

1. Greeting and Blessing of Body at Church Entrance.

2. Entrance procession -- Entrance Hymn -- Tree Song (1).

3. Penitential Rite (Form C).

4. Prayer . . . <u>Little Bits of Love</u>

> Lord you give us little bits of love to be flowers of our day.
> Little bits of love to chase the loneliness away.
> Those little bits of love mean more to us every day, and for these little bits of love I only know I pray that they never go away.
> But away some of them must go, so Good Lord take care of Dottie, our little bit of love, in your own most beautiful and special way.

5. Liturgy of the WORD.

Bible Procession - Hymn "Jesus Loves Me This I Know" (3).
1st Reading - Wisdom 4, 7-14.
Responsorial Psalm - "The Lord is my Shepherd"

Response - The Lord is my shepherd; there is nothing I shall want.
Alleluia - Come, you whom my Father has blessed, says the Lord; inherit the kingdom prepared for you since the foundation of the World. R/Alleluia.
Gospel - Mt 11, 25-30.
Eulogy . . .
Prayer of the Faithful . . . R/Lord, hear our prayer.

6. PRESENTATION OF GIFTS - wine, water, cup, bread, etc.

7. Eucharistic Prayer -- 2.

8. Communion Rite -- Our Father . . . Sign of Peace . . .
Breaking of Bread . . . Communion . . .
Hymn . . . KUMBAYA (6).

Meditation after Communion -- "Heaven's Very Special Child"

9. Prayer after Communion -- A "THANK YOU" FROM A FRIEND.

10. Blessing.

11. Closing Hymn - 1. "I've Got That Joy"
"Love of Jesus"
"Peace that Passeth Understanding"

12. (AFTER MORNING MASS) - Final Commendation and Farewell.

> "If any one of us could bring as much love into the world in one year of our lives as these children bring in one day, oh what beautiful families, countries, world this would be."
> -- Ted and Wanda Wiggins

BRIAN PATRICK DEMPSEY

October 7, 1971 -- October 28, 1976

IN WEAKNESS, STRENGTH

Weakened by his handicap, he returned to his father.--A Double Blessing that he lived, laughed and was among us--all of us motivated and strengthened by his presence.

A JOYFUL EUCHARISTIC CELEBRATION OF LIFE - ETERNAL

1. Welcome and Blessing of Body at Church Entrance.
2. Entrance procession -- Entrance Hymn -- Tree Song (1).
3. Penitential Rite (Form C).
4. Prayer . . . Little Bits of Love

   Lord, you give us little bits of love to be flowers of our day.
   Little bits of love to chase the loneliness away.
   These little bits of love mean more to us every day and for these little bits of love I only know I pray that they never go away.
   But away some of them must go, so Good Lord take care of Brian, our little bit of love, in your own most beautiful and special way.

5. Liturgy of the WORD.

   Bible Procession - Hymn "Jesus Loves Me This I Know" (3)
   1st Reading - Wisdom 4, 7-14.
   Responsorial Psalm - "The Lord Is My Shepherd"

Response - "The Lord is my shepherd;
there is nothing I shall want."
Alleluia - Come, you whom my Father has
blessed, says the Lord;
inherit the kingdom prepared
for you since the foundation
of the World. R/Alleluia.
Gospel - Mt 11, 25-30.
Eulogy . . .
Prayer of the Faithful . . . R/Lord, hear
our prayer.

6. PRESENTATION OF GIFTS -- wine, water, cup, bread, etc.

7. Eucharistic Prayer -- 2.

8. Communion Rite -- Our Father . . . Sign of Peace . . .
Breaking of Bread . . . Communion . . .
Hymn . . . KUMBAYA (6).

Meditation after Communion -- "Heaven's Very Special
Child"

9. Prayer after Communion -- A "THANK YOU" FROM A
FRIEND.

10. Blessing.

11. Closing Hymn -- 1. "I've Got That Joy"
"Love of Jesus"
"Peace that Passeth Understanding."

12. Final Commendation and Farewell.

"May the road rise up to meet you; may the wind be
always at your back; and until I meet you all again
may he hold you gently in the hollow of his hand." Brian

APPENDIX D

BEATITUDES FOR FRIENDS OF THE HANDICAPPED

A "THANK YOU" FROM A FRIEND

BEATITUDES FOR FRIENDS OF THE HANDICAPPED

A "THANK YOU" FROM A FRIEND

1. Blessed are you who took time to listen to difficult speech, for you helped me to know that if I persevered I could be understood.

2. Blessed are you who walked with me in public places and ignored the stares of strangers, for in your companionship I found havens of relaxation.

3. Blessed are you who never bade me "hurry up," a more blessed you who did not snatch my tasks from my hands to do them for me, for often I needed time rather than help.

4. Blessed are you who stood beside me as I entered new and untried ventures, for my failures outweighed the times I surprised myself and you!

5. Blessed are you who asked for my help, for my greatest need was to be needed.

6. Blessed are you who helped me with kindness and gentleness, for often I needed the help I could not ask for myself.

7. Blessed are you when, by all these things, you assured me that the thing that made me an individual was not in my peculiar muscles, nor in my wounded nervous system, but in the God-given self which no infirmity could confine.

8. Rejoice and be exceedingly glad, and know that you gave me and others like me reassurances that could never be spoken in words, for you dealt with me in the true spirit of Christ.

9. Thank you for the memories. I journey with you in spirit on your way of life, as I await with Jesus, our joyful reunion in eternal life.

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