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EXPLORATION OF DEATH CONCEPTS IN THE DEVELOPMENTALLY DISABLED ADULT WORKING IN THE FRANKLIN COUNTY WORKSHOPS

The Ohio State University Ph.D. 1984

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EXPLORATION OF DEATH CONCEPTS
IN THE DEVELOPMENTALLY DISABLED ADULT
WORKING IN THE FRANKLIN COUNTY WORKSHOPS

DISSERTATION

Presented in Partial Fulfillment of the Requirements for
the Degree Doctor of Philosophy in the Graduate
School of The Ohio State University

By

Arlene Holdeman DeRienzo, B.S., M.A.

* * * * *

The Ohio State University
1984

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Adviser

Department of Psychology
DEDICATION

I dedicate this dissertation to Barbara Bolen, the staff person who first said she found talking about death with a developmentally disabled client difficult, and Lisa Kitchton, an employee of FCB MR/DD, who insisted on talking about death with me and started my search for understanding.
ACKNOWLEDGEMENTS

I wish to express my appreciation to my past adviser, Dr. Barbara Edmonson, who was supportive of exploring death concepts in the developmentally disabled, and my current adviser, Dr. Henry Leland, for his willingness to share his mental health philosophy of encouraging focus on health rather than on the "breakdown."

Sincere thanks are given to those at Franklin County Board of Mental Retardation and Developmental Disabilities who assisted in making this study a reality. Most of all I thank the staff who volunteered to be subjects and were interviewed on their own time after work.

My special appreciation is extended to Sandra S. Phalen and Ann Wengler-Thompson who worked long and hard in helping me develop a reliable categorization system.

Sincere thanks to Lynne Collins who was willing to do anything I needed to make this dissertation a reality.

Finally, a double thanks to Linda Crawford for her professional and timely job in typing this manuscript.
VITA

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PUBLICATION

TABLE OF CONTENTS

DEDICATION ................................................................. ii
ACKNOWLEDGEMENTS ................................................ iii
VITA ................................................................................ iv
LIST OF TABLES ........................................................... vii
LIST OF FIGURES ........................................................ viii

CHAPTER

I. INTRODUCTION ......................................................... 1
   Statement of the Problem ........................................... 4
   Purpose ........................................................................ 8
   Hypotheses .................................................................... 8

II. REVIEW OF RELEVANT LITERATURE ......................... 10

III. METHODOLOGY ...................................................... 22
   Population ................................................................... 22
   Purpose ....................................................................... 22
   Subjects ...................................................................... 23
   Instrumentation ........................................................ 27
   Data Collection ........................................................ 29
   Confidentiality ......................................................... 31
   Emotional Well-being of the Subjects ......................... 31
   Categorization ........................................................... 31
   Inter-rater Reliability ................................................. 38
IV. RESULTS ................................................................. 39
   Introduction ......................................................... 39
   Choice of Analyses .............................................. 39
   Interview Reports ................................................ 40
   Test-Re-test Results ............................................ 46
   Hypotheses Test Results ....................................... 52
   Awareness Level of Thoughts About Death ............... 62
   Safer Test ............................................................ 62
   Drawing Analyses ................................................ 63
   Individual Components for the Death Concept .......... 71
   Summary ............................................................. 73

V. SUMMARY, DISCUSSION AND RECOMMENDATIONS ... 74
   Summary .............................................................. 74
   Results Discussion ............................................... 78
   Theoretical Discussion ......................................... 82
   Recommendations ............................................... 88

REFERENCES .................................................................. 90

APPENDIXES .................................................................. 94
   A. Memos to FCB MR/DD July 6, 27, and August 6 . . 95
   B. Letter to Parent or home staff and Questionnaire . 104
   C. Pilot Study Results ............................................. 108
   D. Letter for Staff Volunteers ................................. 110
   E. Consent forms ..................................................... 112
   F. Coding and Interview Recording sheets ............... 115
   G. ABS Administration Directions ............................ 121
   H. Definition of Terms ............................................. 124
   I. Categorization Manual ......................................... 128
   J. Drawing Descriptions .......................................... 207
<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Subject Descriptions</td>
<td>24</td>
</tr>
<tr>
<td>2. Living Situations by Subject Type</td>
<td>41</td>
</tr>
<tr>
<td>3. Reported Deaths of Relatives and Animals</td>
<td>43</td>
</tr>
<tr>
<td>4. Reported Relative Deaths by Age of DD Sample</td>
<td>44</td>
</tr>
<tr>
<td>5. Summary of ANOVA on the WAIS Subtests for Subject Type and Repeated Interview</td>
<td>49</td>
</tr>
<tr>
<td>6. Responses to &quot;Do you ever think about death?&quot; Between Interviews One and Two</td>
<td>50</td>
</tr>
<tr>
<td>7. Changes in Responses Between Interviews</td>
<td>53</td>
</tr>
<tr>
<td>8. Death Category by Intellectual Level</td>
<td>56</td>
</tr>
<tr>
<td>9. Death Category by Sex of Developmentally Disabled Subjects</td>
<td>56</td>
</tr>
<tr>
<td>10. Death Category by Workshop Attended for Developmentally Disabled Subjects</td>
<td>56</td>
</tr>
<tr>
<td>11. Death Category by Age</td>
<td>57</td>
</tr>
<tr>
<td>12. Summary of One-Way ANOVAS on ABS Variables by Death Category</td>
<td>60</td>
</tr>
<tr>
<td>13. Death Categories</td>
<td>61</td>
</tr>
<tr>
<td>14. Responses to the Question, &quot;Do you ever think about Death?&quot;</td>
<td>61</td>
</tr>
<tr>
<td>15. Answers on Safier Test by Type of Subtest</td>
<td>63</td>
</tr>
<tr>
<td>16. Use of Colors for First and Second Drawings</td>
<td>68</td>
</tr>
</tbody>
</table>
## LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Scores for Wechsler Adult Intelligence Scale Vocabulary plus Similarities Subtests</td>
<td>47</td>
</tr>
<tr>
<td>2. Universality and Irreversibility Concept Combinations in DD Sample</td>
<td>72</td>
</tr>
</tbody>
</table>
CHAPTER I

INTRODUCTION

One of the differences between human and other organisms is that we have become aware of our own mortality. Adapting to the knowledge of our mortality is one of the challenges that confronts us especially when death separates us from a loved one. Historically the exposure to death in the family was common. Before this century, a number of babies could be expected to die of common childhood illnesses before they reached adulthood (Gordon & Klauss, 1979). All children were vulnerable, particularly those children who were physically less resistant to illnesses including many children with mental retardation. Many parents of retarded children could expect to outlive the child who was retarded (Wolfensberger, 1976). There was a high probability that the child who did survive and reach adulthood would be exposed to the deaths of siblings or other close relatives. When death occurred it happened frequently with all the family close at hand in the home. The home also was the center of the death rituals as the temporary holding place of the body, concurrent with the family wake.

Today, with the development of immunizations, antibiotics, and other medical advances, it is commonly expected that most children, including those with low physical resistance to illness, will survive childhood and
rarely see the death of a sibling. In addition, the hospital (where it is often the policy to exclude children) has become the place where death generally occurs. Following death the body is immediately taken to a funeral "home" where it is made to look "life-like." Death is no longer easily observable.

With the removal of the immediacy of death from the family and home, children and persons with mental retardation now can be left out easily from the cultural rituals. It is even possible, in many respects, for the family to deny that death has occurred. Children and/or persons with mental retardation can be told things that adults do not believe, but are our cultural "answers" to difficult questions (Emerson, 1977). It may be thought that children and persons with limited thinking ability (who are often confusingly referred to as having "minds of children") are innocent and unconcerned and that it would be cruel to expose them to the tragedies of life (Wahl, 1959). It is not surprising that adults who feel responsible for the well-being of children and persons with mental retardation, are confused about death and what to say about death. We are all confused and have been questioning mortality for centuries, as reflected in religions, philosophies, and medical science.

Until recently, psychologists have done very little to assist in probing this universal human problem (Kastenbaum, 1977). In fact, so little was written by psychologists about death that Herman Feifel (1963, 1974) and others (Bertman, 1974; Croskery, 1979; Groffman, 1974; Leviton, 1977; & Tallmer, 1974) have described death as a "tabooed" subject.

Prior to the late 1950's, there were only a handful of writings by known psychologists related to death. The few writings included Fechner's Little Book of Life After Death, William James' writing on immortality, and
G. Stanley Hall's empirical study concerning fears of death (Kastenbaum, 1977).

The tragedies related to World War I apparently influenced Anthony (1972) in a constructive manner. Anthony became interested in studying the development of death concepts in children. Her early studies prior to 1940, and a study done by Nagy (1948) were among the very few attempts prior to the late 1950's to study empirically the child's early development of death awareness. Both women found independently that children were curious and willing to talk about death. In addition, both found that there were observable patterns concerning the maturation of death concepts which could be viewed developmentally.


Since the publication of The Meanings of Death, death as a subject for research has been studied in a variety of ways, at a variety of age levels with a variety of populations. The topic of death gained enough attention in psychology to be reported in the 1977 edition of the Annual Review of Psychology. In their chapter, Kastenbaum and Costa state that the influence of death on a child growing up continues to be minimized as a force in the texts on development. However, those who currently study death believe that the child's understanding of death is critical to the child's development.
These researchers consider the relationship between development and death concepts one of the current research challenges.

It is now believed that children at very early ages do think and ask questions about death (Kastenbaum & Costa, 1977). The majority of empirical studies regarding children's death concepts did not use subjects younger than three years of age due to the child's inability to communicate (Anthony, 1972; Koocher, 1972; Menig-Peterson, 1977-78; Nagy, 1948; & Safier, 1964). However, there are cases cited of children as early as sixteen months communicating concepts related to death (Bluebond-Langner, 1977; Brent, 1977-78; & Kastenbaum, 1974). Maurer (1966) even believes that the beginning of awareness is observed in the three-month old in his/her fascination with "peek-a-boo." The name "peek-a-boo" is taken from Old English words meaning "alive or dead?" (p. 36).

Statement of the Problem

Despite an increase in research related to death, it is apparent that one specific population continues to be ignored in studies concerning topics related to death. This population consists of individuals who have been diagnosed as having mental retardation and/or are developmentally disabled.

Several educated guesses could be made concerning why there is an absence in this area. One, alluded to previously, is that psychologists and the general public, have assumed that persons with limited thinking ability do not think about death; therefore, we do not need to concern ourselves with studying death concepts with mentally retarded individuals. Another could be that there are many other areas of concern which have had a higher priority in meeting the needs of the mentally retarded such as better living standards exemplified by the philosophies of deinstitutionalization and normalization. A
third speculation about why we have not studied death concepts of the mentally retarded is that formerly the short life expectancies of the mentally retarded made it less of a necessity to help provide them with appropriate outlets for grieving or to develop a means of gaining an understanding of death.

During the past several years, this writer has had the opportunity to observe and interact with developmentally disabled persons. During this time several deaths of parents as well as deaths of persons who worked at a workshop employing developmentally disabled adults have occurred. Perhaps these deaths were stimuli for those who worked at the shop or sensitized this writer, a psychology intern employed at the workshop to provide psychological services, to the impact of death on persons who are developmentally disabled. How the awareness began is difficult to trace now; however, what is important is that these adults were observed to be aware of the deaths and clearly wanted to discuss them. The observed anxiety, questions and concept levels about death appeared to vary. It became apparent that past experiences with death, as well as what adults had told these persons, frequently led to confusion. This confusion, in turn, seemed related to the anxiety many of them expressed. Sometimes, but not frequently enough, the confusion was easily identified and corrected. This writer turned to the literature for assistance in understanding the problems and questions which were more difficult to resolve. It soon became apparent that little had been done in studying how the mentally retarded view death.

There was one study which reported that the developmentally disabled are often treated differently by our culture with regard to death events. Stacey and Reichen (1954) gave a questionnaire on the topic of death to two
groups of adolescent girls (ages 14 to 16 years). The focus of this study was meant to establish that intellectually subnormal adolescent girls were treated differently regarding death events compared to intellectually normal girls. However, the authors began with differential treatment because the intelligence instruments used to separate the two groups were different. Consequently, Stacey and Reichen's (1954) results are questionable.

Prior to 1981 there had been no additional studies which examined death concepts specifically in a developmentally disabled population. However, two articles had been written which voiced concerns shared by this writer. A mother of a sixteen-year old mentally retarded girl wrote, "...—how fully do we let our mentally retarded children experience this full range of emotions; and how can we honestly interpret their total humanness to others, if we, their parents, are less than honest with them? And honesty includes our preparing them for sickness and dying. They deserve no less than this" (Moise, 1978, p. 398).

The second article (Emerson, 1977) expressed an additional perception: Two of the most powerfully denied elements of our culture are death and retardation. When these two intersect, as with a retarded individual grieving the loss of a friend or family member, the powerful cultural avoidances seem to make it difficult for other people to comprehend the emotional responses involved (p. 46).

Emerson (1977) presented experiences from her work as a consultant for several residential facilities (ranging from family homes to larger institutions) for developmentally disabled persons. Emerson frequently was contacted when persons suddenly showed changes in behavior: e.g., verbally
or physically aggressive or extremely withdrawn. In these crisis interventions, she found that, "... about 50% of the time there has been either a death or a loss of an individual close to the client preceding the onset of symptoms" (p. 46).

In the times that death had preceded the overt behavior changes, Emerson found also that persons in the environment handled the information about death by denying it or by expressing, in a variety of ways, rejection of the feelings of the developmentally disabled person.

Emerson's (1977) work needs further exploration and is addressed in this study using the AAMD Adaptive Behavior Scale (Nihira, Foster, Shellhaas, & Leland, 1974).

In April, 1983, Mental Retardation published the first research concerning death perception of the mentally retarded adult. The authors, Lipe-Goodson and Goebel (1983), investigated specifically the relationship of age, IQ, sex, and percentage of life institutionalized to the resulting perceptions of age and death. Although this study appears to be more interested in age perception, the results suggested that there is a developmental process involved in age perception of others and that the concept of death in mentally retarded adults is similar to that of nonmentally retarded children.

Our society has been encouraged through studies such as those by Anthony (1972) and Nagy (1948) to recognize that children are aware and curious about death. Current advocates in the area of death education for children, such as Feifel (1963, 1974, 1977), Grollman (1967, 1974), and Kastenbaum (1967, 1977) have emphasized that excluding a child from death-related phenomena does not keep the child safe and innocent, but
Instead often leads to confusion. From studies pertaining to death concepts of children, more appropriate methods of handling death related events have evolved. Hopefully our society will be encouraged also through studies of death concepts involving persons with mental retardation and/or developmental disabilities to recognize healthy ways of preparing them for and handling the realities of their death experiences.

**Purpose**

The purpose of the present study was to do an exploratory investigation of awareness and the concepts of death in the developmentally disabled adult working in the Franklin County (Ohio) Board of Mental Retardation and Developmental Disabilities workshops. Of particular interest was whether there were concepts expressed by this population which could be categorized into a developmental model. Of further interest is the prevalence and types of distortions about death and perceived, related events. In addition, the relationship between adaptive behavior and death concepts was explored using the AAMD Adaptive Behavior Scale since there was some indication by Emerson (1977) that behaviors do change following death experiences.

**Hypotheses**

The following hypotheses were tested in the current study. All are stated as predicted hypotheses.

1) Responses given by persons who are developmentally disabled can be reliably categorized into death categories.

2) There is a relationship (p<.05) between the previously measured level of intellectual functioning of the subjects and the death categories.
3) There is no relationship between sex of subjects and the death categories.

4) There is no relationship between the workshop attended by the subjects and the death categories. (Workshop is by location, North and West. A developmentally disabled individual is assigned to a workshop by geographic location of residence).

5) There is no relationship between age of subjects and the death categories.

6) There is a relationship (p<.05) between the adaptive behavior of subjects and the death categories.

7) Responses given by the group of persons who are developmentally disabled are significantly different (p<.05) from the group of workshop staff in death categories.
CHAPTER II

REVIEW OF RELEVANT LITERATURE

A search of the literature revealed that death concepts of developmentally disabled persons have only begun to be investigated. The most relevant study (Lipe-Goodson & Goebel, 1983) examining the development of death concepts in the mentally retarded adult, has found development of death concepts in the retarded to be similar to the development in nonmentally retarded children. Therefore, the developmental perspective based on studies with intellectually normal children was useful in establishing the conceptual framework for this study.

The early developmental work concerning death began in Europe. Among the first published developmental studies was a book, written in Hungarian, in 1936 by Nagy, titled The Child and Death. Nagy's English translation, for which she became known in the United States, was published in 1948.

Nagy investigated the development of the child's attitude and knowledge regarding the nature of death. The 378 subjects, 3 through 10 years of age, consisting of 51 percent males and 49 percent females, were from Budapest and reportedly represented a range of social class, educational backgrounds, and religions. Nagy used three methods of investigation: 1) Compositions written by children aged 7 to 10 years, 2) drawings done by children 6 to 10 years of age, and 3) discussions with all of the children.

Nagy was able to categorize the replies to the question, "What is death?", into three groups. She also found that the groups were related to
the age of the subjects and consequently discussed these groups as "stages of development."

In the first stage the child, approximately age 3 to 5 years, views death as a departure or sleep. The young child denies death. Death is merely seen as living under changed circumstances. Nagy observed that as age of subjects increased, so did their acknowledgement of the existence of death. Around 5 to 6 years of age, the subjects expressed that death happened gradually, that there could be degrees of death, and that death was temporary.

Nagy's second stage included subjects ages 5 to 9 years. This stage was associated with the child who explained death as a person who caught some people. If one were clever, death could ultimately be escaped. One-third of the children at this stage identified a "death person" with the dead. Children at this stage continued to indicate confusion concerning the permanence of death. They associated death with darkness.

Nagy's third stage included children over age 9 who see death as an internal process rather than an external agent. A child at this stage also recognizes that death is final and that everyone dies. Death is thought of as "the cessation of corporal life."

Anthony (1972) began to study death concepts in children living in Great Britain before 1939. She also used three methods of investigation: 1) Systematic observations of children recorded by parents, 2) a vocabulary test including the word 'dead,' and 3) a story-completion test. Anthony had a total of 128 boys and girls. The sample was taken largely from the urban areas of Great Britain. Anthony's study included a small percentage of educationally subnormal children (8.6 percent, 13 subjects).
Anthony observed a developmental pattern in the qualitative changes in the concept of the dead associated with age. Moreover, the age association was somewhat closer to mental age than to chronological age.

Anthony grouped the responses into five categories as follows:

Category A: A lack of knowledge, concern, or interest in the concept. This level was observed in children under the age of 5 years.

Category B: An interest, but limited and possible erroneous concepts, are characteristics of this stage. Typically, 5 and 6 year olds express that being "dead" is like "going to sleep."

Anthony stated that the child moves from Category A (no awareness) to Category B at the same time he/she changes his/her focus from "what" or labeling questions to "why" questions. The focus in cognitive development at this time is on the concept of cause. Death, as a concept, emerges at this time. The child, although emphasizing causality in his perception of reality, includes many misinterpretations with regard to "cause" in his explanation of death events.

Category C: The 6 to 9 year old makes correct statements with regard to 'dead,' but does not have the ability to prioritize or logically establish the biological essentials related to death.

The age of 7 was found to be significant to Anthony because all 7 year olds responded in the C Category. (Anthony attributed some of this to the results of school conformity, but felt that not all of the responses of the 7 year olds could be fully explained by this reason since school in England is compulsory from 5 years of age). Children at the C level and above began to
define dead as the negation of living and were preoccupied with ceremonial and personal experiences with death.

Category D: 9 and 10 year olds are beginning to combine logical and biological essentials to the definition of dead but as yet have not made generalizations which refer to all biological life (the tendency was to discuss only humans). At this level there is no apparent lack of ability in understanding the event or word, but the response excluded or did not present a sufficient generalization.

Category E: This fifth stage is found in 11 and 12 year old children. Anthony's last stage specifies the knowledge that death is universal. Children include all logical and biological essentials in their definitions. The most complete short response cited by Anthony in Category E is, "A body that has no life in it." (p. 54).

Anthony (1972), as stated previously, also had subjects who were assessed to be intellectually subnormal. She interviewed 13 subjects, aged 9 through 13 years. The results from the subnormal subjects, regrettably, were not fully reported. However, the category of responses of these subjects is available.

The majority of the subjects' (10) responses were of the C-category type. Category C is a response that includes comprehension of the word dead, but the definition refers to associated phenomena that are not biologically or logically essential, or only refers to humans.

One subject, age range 9 to 9 years 11 months, and the youngest of these subjects, gave an A Category response (apparent ignorance of the word
dead), while two subjects (one in each category), both in the age range 13 years to 13 years 11 months, gave responses of the B category (interest in the word or fact combined with limited or erroneous concepts) and the D Category, respectively (the D Category includes correct, essential information with limited generalization).

Recent researchers of children's concepts of death have used Piaget's cognitive development as a basis for their categories. Although Piaget (1951) did not study death, he did examine the phenomena "animism." Animism, as used by Piaget, refers to the child regarding inert objects as living and conscious. Piaget presented a developmental continuum which begins with no separation between mind and matter. He ascribed four observable phases which he placed on a continuum which each child will follow in a regular, unmodifiable, necessary sequence. A child in the first stage associates consciousness to all things. The child in the second stage only attributes consciousness and life to things which move. The third stage is expressed if the child attributes consciousness to things which only move of their own accord. The child in the final, and fourth stage restricts consciousness to animals (includes humans but excludes plants). Piaget found that Swiss children usually achieved adult understanding of animism between 8 and 11 years of age.

The relationship between "animism" and "death concepts" was examined by Safier (1964). Her study, based on the theoretical work of Nagy and Piaget, consisted of 30 boys, ages 4-11 years. Safier used 10 stimulus words: dog, ball, tree, bike, boy, moon, mother, ocean, car, and cloud. Each stimulus word was placed in a sequence of four questions.

Question 1: Does a ______ live? Is a ______ living?
Question 2: Does a ________ hurt when hit?

Question 3: Does a ________ grow up?

Question 4: Does a ________ die?

Safier gave each subject one point for every animistic response. All points were summed and the child's performance was assigned an "animism" score. The higher the score, the lower the stage of development. A "death score" was computed by adding the negative animistic responses to Question 4. In other words, a score of one point was given if an inanimate object is said to "die." Five categories were constructed by Safier to be used in judging the responses of the subjects. Two of Safier's categories were used for recording interviewer or judgment difficulties. The remaining three categories are similar to Nagy's, although labeled differently:

**Flux:** The child believes life and death are temporary. This category was observed predominantly in the 4-5 year old subjects.

**Yes and No:** The child at this level states that you can escape from death, but if caught, cannot come back to life. If any subject indicated personification of death, he was automatically assumed to be in this category.

**Adult and Pseudo-Adult:** The child has begun to think about death as most adults think of death. Death was known as a permanent event which is not escapable. Death could be misapplied to objects such as a ball or car but still judged to be in the "Pseudo-adult" category.

The oldest group (10-11 year olds) showed an indication of a greater integration toward mature, adult reality while the youngest group (4-5 year
olds) viewed life and death globally with everything as alive but in constant flux between life and death. Safier found that the concepts of animism and death were related but that in the transition from the global to the well integrated state, there is a lesser degree of relatedness.

Childers and Wimmer (1971) conducted a study of the cognitive awareness of death as a universal and irrevocable event using boys and girls aged 4 through 10 years. The primary method of study was individual discussions with the subjects which included these questions:

1) Say whatever comes to your mind about death.
2) Have you seen anyone dead?
3) Tell me about it.
4) What are some things living people can do?
5) Which of these can dead people do?
6) Does this mean they can come back to life?
7) Does everybody die?
8) Will everybody die? (p. 1300).

The children were asked also to either draw or write about what death meant to them. Childers and Wimmer's results demonstrated that children have an awareness of universality with a "sporadic progression in understanding as the age level increases" (p. 1301). On the other hand, results did not demonstrate that irreversibility was a function of age. In fact, this particular study found that, although not significant, some 4 year olds (3 subjects) responded correctly to the irrevocable (irreversibility) concept questions. However, overall, two thirds of the children were uncertain or wrong about the finality of death.
Koocher (1972) studied the developmental relationship between personality, cognition, and death concepts in children. His study included 75 children ranging in age from 6 to 15 years. The sample had approximately 20 percent nonwhite children and included both boys and girls of normal to above normal intelligence measured by their performances on the Similarities subtest of the Wechsler Intelligence Scale for Children. Koocher asked four questions, interspersed among other items in the assessment for each subject (Assessment consisted of the Index of Adjustment Values test, WISC Similarities subtest, and Piagetian cognitive judgement tasks). The death concept questions were:

1) What makes things die?
2) How do you make dead things come back to life?
3) When will you die?
4) What will happen then (when you die)? (p. 7-8).

Koocher classified the subjects' responses into three classes:

Class 1: Included fantasy reasons, magical, and realistic causes marked by egocentric reasoning.

Class 2: Included specific means of inflicting death. This level was observed to include more answers of death by violence than any other reasons given explaining the cause of death.

Class 3: Responses in this class described death as a natural process and included abstract clusters or generalizations rather than the more specific responses found in Class 2. Specific causes were used as illustrations in broader classes such as "old age," "illness," and "body wearing out."
Koocher found no significant sex or racial differences. He did find that the classification of the replies to the death questions were related to the child's level of cognitive development as measured by the responses to the Piagetian tasks. Changes in the expression of understanding the cause of death were observed to be related to maturational differences (the Preoperational stage compared to Concrete Operational, and Concrete Operational stage compared to the Formal Operations stage). The results of Koocher's irreversibility questions (How do you make dead things come back to life?) differed from the results of Childers and Wimmer's (1971) study. Koocher found that only 8 of his 75 subjects indicated that they thought that it was possible to come back to life after dying. All 8 of the subjects responding incorrectly to this question were judged to be at a Preoperational level on the Piagetian tasks (40 percent of the Preoperational subjects). No Concrete or Formal Operations subject expressed this belief. (The age range of Preoperational subjects was 6-11 years with a mean age of 7.4 years.)

Kane (1975) examined components of the death concept as related to age and experience. Experience was defined by Kane as knowing some person (close to the subject) who had died. Those subjects who had experience were compared to a group of children who had no experience. Kane's 122 subjects ranged in ages 3 through 12 years and were interviewed with the use of nine rabbit pictures which included one picture of a sleeping rabbit and one picture of a dead rabbit. The results of the study revealed that the development of the death concept is steady and rapid from ages 3 to 9 years, but did not occur evenly from ages 10 to 12. Experience was found to make a difference only in concept development at the earlier ages (ages 3 to 6 years). The order of acquisition of the components were found to vary
between the experienced and inexperienced children. The three components which differed were dysfunctionality (the component which deals with some idea about bodily functions of the dead other than senses), insensitivity (the component considered to involve the presence or absence of sensory functions in the dead) and causality (the component which concerns the child's ideas of what causes death).

Kane found also that the development of the death concept appeared to follow three consistent stages. Kane, like Koocher, modeled her stages from Piagetian periods:

Stage One has completely to do with structure, how the dead are and where they are.

Stage Two has to do with function, the working of the body in the here and now and in the forever.

Stage Three has to do with abstractions regarding death. (p. 109).

Lonetto (1980) assessed 201 children, 3 years 5 months to 13 years of age, in Ontario and British Columbia. Subjects were asked to draw pictures concerning death and to discuss their drawings and feelings about death. Systematic analysis of the color and content of the drawings and the responses to four questions were analyzed. These questions were:

1) What happens to people when they die?
2) Do you ever think about death?
3) Does everyone die?
4) Will you die some day?

Lonetto found that his subjects' responses fit into three stages.
Stage One: consisted of children on the average of 3 through 5 years of age. These children expressed magical-cyclical ideas which indicated that life and death were interchangeable and that death was living under changed circumstances.

Stage Two: consisted of children aged 6 through 8 years who conceived of death as being an external agent. Death was a person who can either catch you and take you away or from which people can work hard to escape. These children are also interested in the rites of burial.

Stage Three: the adultlike stage in which the children whose thinking viewed death as the end of life and thought about death in abstract terms. The subjects who responded at this level were approximately 9 years of age and older.

To summarize, the studies regarding the development of death concepts have included children between 3 to 16 years of age. Different stages of thinking have been found and described using as few as three and as many as five stages. Pooling the result of all of the studies, it would be possible to conclude that the most mature children expressed that:

1) Death is irreversible, final, permanent;
2) Death is inescapable, inevitable, universal;
3) Death is an internal process which is the cessation of corporal life caused by injury or illness; and
4) Death is perceptibly recognized as the cessation of the essential body signs consisting (in humans) of brain waves, breathing, and heart beating.
Most of the studies found that chronological age and, more importantly, mental age, was found to correlate highly with the qualitative differences in the type of responses regarding the concept of death. Consequently, the qualitative differences are referred to as levels or stages.

If professionals, who work with mentally retarded/developmentally disabled persons, are to be knowledgeable in providing appropriate outlets for grieving and helping them develop a means of gaining a useful understanding of death, we need to know more about what their level of thinking is regarding death.

Thus, the present investigation sought to explore the development of the death concepts of developmentally disabled adults. The purpose of the study was to contribute to the understanding of the mentally retarded/developmentally disabled adults with regard to how they think about death.

The following chapter will present the specific methodological issues and details of how death was studied in a developmentally disabled, adult population.
CHAPTER III

METHODOLOGY

Studies with the developmentally disabled must take into consideration language, attention-span, reaction time, learning, and abstract thinking deficits potentially found in this population. With these limitations taken into consideration, the interview method was judged to be most useful in studying death concepts in the developmentally disabled adult. Questions from earlier developmental studies, adapted for a more simple and concrete format, were used.

Populations

The population studied was comprised of the Franklin County Board of Mental Retardation/Developmental Disabilities ARC-Industries workshop employees.

Although, question by question, it would be possible to compare superficially the present results from the children's responses in previous studies, it was decided that a sample from an adult population of normal (or above) intellectual functioning was needed to provide this study with a basis for adult response comparison. An available population was the staff working with the ARC-Industries employees, who share the same work environment for part of the day.

Purpose

The present study was designed to explore the awareness and concepts of death in the developmentally disabled adult working in the Franklin County Board ARC-Industries workshops. In addition, of particular interest is what categories are identified from responses in an interview.
Subjects

Experimental sample selection. A sample of 48 adult subjects was selected. They ranged in age from 21 to 60 years and were employed at the Franklin County Board's ARC-Industries sheltered workshops for persons who are mentally retarded and/or significantly developmentally disabled. Half of the subjects were male and half female (24 males and 24 females). Subjects were selected in the following manner: the records of the Franklin County Board of Mental Retardation/Developmental Disabilities were examined for currently enrolled persons. The file search included the name, age, sex, workshop, intelligence testing instrument used most recently, most recent level of measured intelligence and birthdate. All persons whose birthdates were before July, 1951 and working at the West or North workshops and who were assessed to be functioning intellectually at Level I, II, or above (Grossman 1977) at the time of the most recent assessment, were recorded on the researcher's sampling sheets. Subjects were then stratified by workshop, age, sex, and functioning level. Forty-eight subjects were randomly selected using these variables. Table 1 is a summary of subjects and the variable identifications for the North and West workshops. (The workshops are geographically placed in Franklin County and are sheltered places of employment for developmentally disabled persons. This variable was assumed to not make a difference but was controlled to prevent it as an error factor). The sample which resulted consisted of 3 persons in each cell: same workshop, level of functioning, sex, and age group. There were 48 persons targeted for the original sample with 16 persons as a reserve sample.

1 There were 277 persons at the two workshops meeting these criteria.
TABLE 1

Subject Descriptions

<table>
<thead>
<tr>
<th>Subject</th>
<th>Sex</th>
<th>Age Level</th>
<th>Intellectual Functioning Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subject 117*</td>
<td>male</td>
<td>young adult</td>
<td>11</td>
</tr>
<tr>
<td>Subject 118</td>
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<td>young adult</td>
<td>1</td>
</tr>
<tr>
<td>Subject 119*</td>
<td>male</td>
<td>young adult</td>
<td>11</td>
</tr>
<tr>
<td>Subject 120</td>
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<td>middle age</td>
<td>1</td>
</tr>
<tr>
<td>Subject 121</td>
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<td>young adult</td>
<td>11</td>
</tr>
<tr>
<td>Subject 122*</td>
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<td>young adult</td>
<td>11</td>
</tr>
<tr>
<td>Subject 123</td>
<td>female</td>
<td>young adult</td>
<td>11</td>
</tr>
<tr>
<td>Subject 124*</td>
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<td>middle age</td>
<td>11</td>
</tr>
<tr>
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</tr>
<tr>
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<td>middle age</td>
<td>11</td>
</tr>
<tr>
<td>Subject 128*</td>
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<td>middle age</td>
<td>11</td>
</tr>
<tr>
<td>Subject 129*</td>
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<td>young adult</td>
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<td>Subject 130</td>
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<td>11</td>
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</tr>
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<td>Subject 136*</td>
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<td>middle age</td>
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<tr>
<td>Subject 138*</td>
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<td>middle age</td>
<td>11</td>
</tr>
<tr>
<td>Subject 139</td>
<td>male</td>
<td>middle age</td>
<td>11</td>
</tr>
<tr>
<td>Subject 140*</td>
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</tr>
<tr>
<td>Subject 141</td>
<td>male</td>
<td>middle age</td>
<td>11</td>
</tr>
<tr>
<td>Subject 142*</td>
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<td>young adult</td>
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</tr>
<tr>
<td>Subject 143*</td>
<td>female</td>
<td>young adult</td>
<td>11</td>
</tr>
<tr>
<td>Subject 144*</td>
<td>female</td>
<td>young adult</td>
<td>11</td>
</tr>
<tr>
<td>Subject 145*</td>
<td>male</td>
<td>young adult</td>
<td>11</td>
</tr>
<tr>
<td>Subject 146*</td>
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<td>middle age</td>
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</tr>
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<td>Subject 147</td>
<td>male</td>
<td>middle age</td>
<td>11</td>
</tr>
<tr>
<td>Subject 148*</td>
<td>male</td>
<td>middle age</td>
<td>11</td>
</tr>
<tr>
<td>Subject 149*</td>
<td>male</td>
<td>middle age</td>
<td>11</td>
</tr>
<tr>
<td>Subject 150*</td>
<td>male</td>
<td>middle age</td>
<td>11</td>
</tr>
</tbody>
</table>

*Subject repeating interview
This sample list, which included both the sample and the reserve sample, was given either to the rehabilitation specialist or language specialist who knew the subjects in order to screen out those potential subjects who had deficits in expressive language which would prevent them from being understood within an interviewing context. Following this screening, each of the remaining subjects was asked if he/she would consider being a participant in the study. If the individual indicated that he/she wanted to help with the research, he/she was given a letter to take home. The letter notified the persons at the individual's residence of the study and gave the researcher's phone number to call if there were any questions (See Appendix B).

Signed consent. All subjects agreed to participate and signed a written consent at least one day prior to participation. The reading, verbal explanation, and signing was witnessed by a staff person for each individual (usually the instructor or case manager of the individual). All subjects were their own guardians so no guardian permission was required. Each participant was informed that he/she could change his/her mind even before the interview was over or he/she could refuse to answer any question during the interview.²

Following the interview each subject was asked to sign a written release of information for the researcher to obtain a current AAMD Adaptive Behavior Scale (ABS) assessment. All subjects, with one exception, signed a release for the ABS.

² Two subjects refused to do the interview after signing a consent. Of those who were interviewed, no one left prior to completion. Some refused to draw a picture, but no subject stated that he/she did not want to answer a question.
An interview retest (described separately) was done on 16 of the original subjects. The same consent form and procedure (as described above) was repeated for each of these randomly selected subjects.³ (See Table 1)

**Payment of subjects.** Each subject was paid his/her hourly wage for an hour or the time participated if longer than an hour. Payment was made with a personal check by the researcher.

**Volunteer comparison sample.** Staff, who were assumed to be of normal to above normal intelligence, working at ARC-Industries North and West were asked to volunteer to participate in the study. From those who volunteered, 10 persons were selected from each workshop (total n=20). There were 5 males and 5 females from each workshop. Age was not controlled, although this information was obtained from each subject (no subject was over the age of 40 years and all were above 21 years of age). These volunteer subjects signed a written consent to participate. No staff person was paid by the researcher for participation. This sample was interviewed to serve as an exploratory indicator of what adults who were not mentally retarded/developmentally disabled, would answer in the interview.

³ Subjects were not notified ahead of time since it would most likely lead to confusion because of the abstract concept of chance.
Instrumentation

Development. A structured interview was constructed by this researcher. Most tasks and questions were selected from previous research done predominantly with intellectually normal children. For the purpose of this study, the sequencing and questions were adapted to be used with persons who are developmentally disabled. The instrument was tested in a pilot study consisting of four consenting males and four consenting females who worked at ARC-Industries West workshop as employees and had previously been in therapy with the researcher. Two interviews occurred with each of these individuals to test for 1) the reliability of the instrument, 2) the validity of the instrument, 3) the DD subjects' ability to understand the questions, 4) the sequence of the questions, 5) miscellaneous instrument components such as time constraints and scoring sheet design, and 6) questioning and interviewing skills (on the subject of death) of the interviewer. All interviews were done by one person, this researcher.

Interview description. Each subject was interviewed in a room away from the workshop work area. The same rooms were used during the duration of the study at the respective workshops.

The subject was requested initially to answer questions on the Vocabulary and Similarities subtests of the Wechsler Adult Intelligence Scale. The Vocabulary subtest was used to get a quick assessment of the person's vocabulary and verbal intelligence. The Similarities subtest, as in the Koocher (1972) study, was used as a quick way of assessing 1) verbal concept formation, 2) abstract reasoning, and 3) general intellectual functioning level. In addition, the results of these two subtests was a way of establishing that the staff volunteers represented a separate population.
Each interview began by requesting the subject to "Draw death." For the purpose of the drawing, each subject was given a white sheet of paper measuring 8 1/2" x 11" and a container of 8 watercolor, felt-tip markers. The colors in the container were black, brown, red, yellow, green, blue, orange, and purple. The same brand and type of markers were used for all drawings. These same supplies were used also for the last request in the interview, "Draw anything you want to draw."

The question portion of the interview was administered according to the order indicated on the recording sheet (See Appendix F). Each person was asked each question. If the person had previously addressed a question, the person was asked if there was anything that he wanted to add to that particular question noting that the interviewer was aware that the subject had addressed it in a previous question. No subject appeared to object to repetition of a question when it was presented in that manner.

Twelve parts of the interview were examined in terms of the responses given by the eight pilot subjects between interviews one and two to determine test-retest reliability of the instrument. The reliability of the scores on the Wechsler Intelligence Scale (WAIS) subtests, the Saffier Test, and responses to the question, "Do you ever think about death?" were all tested using a Pearson's Product Moment Correlation. In addition, the WAIS scores were tested with a paired t-test to see if there was an overall average change in means due to repeated measures of subjects with the same instrument. The WAIS score reliability (Pearson's Product Moment Correlation) was quite high (r = .92). The paired t-test found no significant change (t = -1.21, df = 7, N.S.). The Saffier Test correlation was not reliable (r = -.06). This is due to more subjects responding correctly the second time.
Two possible explanations are that learning occurred as a result of the first interview and/or interest in death increased. The opposite happened on the WAIS with five subjects getting lower scores for the second administration. The answers to the question "Do you ever think about death?" were found to change between interviews. Six subjects acknowledged some thoughts about death ("yes," "sometimes," "not often") the first time. At the second interview, only four subjects acknowledged some "death" thoughts (r = .58). The remaining nine parts of the interview were examined for the percent of agreement with the same or similar responses (for each subject) for the two interviews. An average for the nine remaining parts was 70.83% agreement. (Appendix C presents a list of the percentage of agreement for each of the individual part of the interview).

Data collection

Interview. During the interview, the interviewer wrote the essential parts of each subject's answers on a printed recording form. A separate recording form was used for each interview. In addition, the interview was recorded by an audio tape recorder. Following the interview, the recording sheets were skimmed for omissions or unclear statements. The audio tape of the interview was used to clarify a small number of the written recordings. The recorded audio tape was referred to, as needed, when response categorizations were done.

Repeated interview. During the pilot study unexpected changes in answers (between the first and second interviews) occurred in some of the responses to the question, "Do you ever think of death?" This observation led to the question of whether any other or similar changes would occur in a larger, random sample. (The pilot sample was possibly different due to having
been previously identified as needing psychotherapy). In order to examine if a larger group of subjects would change similarly, some of the subjects were interviewed a second time. The second interview was done with a random sample (no stratification was used for the second interview) of 8 subjects from each workshop (DD n=16) and 5 volunteer staff members from each workshop (SV n=10). The total number of persons who were interviewed twice was 26. The interview was completed in as similar a manner to the first as possible. The length of time between interviews was no less than 4 days and no more than 14 days. The length of time between the first and second interview was not controlled. The second interview consistently took less time (approximately 10 minutes less).

**Verifying death experience and current living situation.** Each developmentally disabled subject, unless he/she lived independently, was given a questionnaire to be taken home. A person at home was asked to fill out the questionnaire (See Appendix B). The questionnaire was used to obtain information regarding 1) current living situation, 2) the death experience of the subject, 3) the time since the death(s) occurred, 4) relationship of known deceased persons to subject, 5) cause of death, if known, and 6) accuracy of subject's information stated in the interview.

**AAMD Adaptive Behavior Scale assessment.** The subjects' case managers, at the ARC-Industries workshop, were given AAMD Adaptive Behavior Scales (Nihira, Foster, Shellhaas, & Leland, 1974) to complete during the month in which the interviews were conducted. A brief, two page summary of administrative procedures (as a review and also for control of quality of response) was given to the respective case managers (See Appendix G). In order to make this task less time consuming for the case
manager, the identifying information was filled out prior to giving the scale to the case managers. All completed scales were scored and profiled by the researcher. The profiles were copied and the completed ABS was returned to the workshops for program use.

If a protocol had been completed by a workshop staff person within the past six month period, that protocol was used instead of completing a new one. Protocols meeting this criteria were available for two subjects.

No measurement of adaptive behavior was done with the adult comparison group of staff volunteers.

Confidentiality

All information obtained through this study was kept confidential. The recording sheets for the interviews were labeled only with codes. All of the research is reported without names. Each interview was tape recorded in a private room with all tape recordings labeled only by code.

Emotional Well-being of the Subjects

This researcher took precautions to be alert for any subject who might require some psychological services to assist him/her in dealing with death and in particular, in dealing with the interview.

Categorization

Development. Categorization was developed after the data were collected. The first step in developing the categorization system was to combine those previous researchers' levels or stages which appeared to best describe the development of the death Concept. Since the development of death concepts has been found to correlate with cognitive development (Kane, 1972; Koocher, 1972; Safier, 1964), this researcher chose to use three Piagetian based levels of categories with subgroups, as needed.
Consequently, Category 1 was thought of as basically a Preoperations level of thought processes; Category 2, Concrete Operations; and Category 3, Formal Operations. The definitions were developed by combining previous researchers definitions and placed in the Categorization Manual (Appendix I). The categories are as follows:

**Distortion**

It is unclear what the person knows based on the interview. This is apparent from answers which are 1) not appropriate to the question, 2) disagrees with previous statements he/she made, and/or 3) the person makes no attempt to qualify or resolve the conflict in logic.

**Category 1**

This category includes all responses which are answered negatively to the questions, "Does everyone die?" and "Will you die?".

- **Category 1a** is the category which indicates overall ignorance and an unconcerned approach to the subject. All the answers given are either "don't know" or answers which appear as though the answer is given to comply with the interviewer's requests. These interviews are often done by persons with very primitive levels of drawings, but not consistently.

- **Category 1b** is the category which indicates that the person has enough awareness about death to get some appropriate information which, on the face value of the answers, appears to be correct. This is often
found in the direct experiences of the person, in that the individual has known an animal or a pet that died. The separation between 1a and 1b is the difference between whether the responses indicate curiosity and awareness or not. The curious, and the persons with some semblance of knowing anything, even though marginal and incorrect, are category 1b.

Category 2
This category includes the responses which indicate a lack of knowledge of either universality or irreversibility. This category often includes a great deal of information about death which may be irrelevant and/or inaccurate. There are often many descriptions about what happens to the body and other burial rites which may be accurate.

Category 3
This category is generally an adult or pseudoadult level of conceptualizing death. This category describes responses which almost always expresses an accurate knowledge about both universality and irreversibility. In other words, those who fit into this category have answered "yes" to "Does everyone die?" and "Will you die?" and "You can't" to the irreversibility question (or other acceptable statements).

Category 3a includes those interview responders who recognize that death is final and that everyone will die, including himself/herself, but does not express very much other information and may add very little
to his/her answers about "What makes people die?" and "How can you tell when someone is dead?". This category, for these two questions, state more specific examples with very little evidence of making the generalizations required for Categories 3b and 3c.

Category 3b recognizes some basic death symptoms to "How can you tell when someone is dead?", but is not sophisticated enough to state anything to do with such things as the brain stopping or that there are no brain waves.

Category 3c is the category which has good generalization development for the questions, "What makes people die?" and "How can you tell when someone is dead?". Typical responses would have generalizations with or without specific examples. For example, in response to "What makes people die?", this type of responder would say something like "Illnesses of different kinds and accidents, both of which impair the body to function and maintain life."

In response to "How can you tell when someone is dead?", this response category would include something to do with body functions ceasing and especially the essential ones which are easily observable; breathing stops, the heart stops. These subjects may also include such things as the person's
face appears different, touching them feels cold, the
body turns stiff, and color changes.

A decision chart was developed for consistency when making the
decisions required to place subjects' interview responses into the appropriate
categories. The first step was to identify the components which were needed
to separate the interview responses into categories. This was accomplished by
reviewing many of the interviews for the common elements which
distinguished the different levels based on previous developmental studies. The
differentiating elements, stated as questions, were then ordered from the most
complex and least often answered appropriately, to the most simple and most
often appropriately answered. This was put into an abbreviated chart. The
manual consisted of an explanation of the rationales and use of the chart.
Each box from the chart, labeled a section, was numbered. Each section
described the corresponding box. In addition, examples of acceptable and
unacceptable responses were listed for more clarity (See Appendix H for
Manual and decision-making Chart).

A categorization recording sheet was used for recording the summary
of the decision chart. This sheet consisted of a listing of the components of
the decision-chart and was used by making statements under the concept
label such as "o.k.," "no," "good generalization," or specific listings such as
"cancer," "car wreck," "coffin," etc. At the top of the sheet the subject's
code number, category, and corresponding computer number were placed.

During the initial categorization procedure, it became evident that a
few subjects had not been screened carefully enough for language problems.
Responses were very difficult to understand (or included perseveration and
echolalic responses) or the subjects gave personally conflicting responses
face appears different, touching them feels cold, the
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described the corresponding box. In addition, examples of acceptable and
unacceptable responses were listed for more clarity (See Appendix I for

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During the initial categorization procedure, it became evident that a
few subjects had not been screened carefully enough for language problems.
Responses were very difficult to understand (or included perseveration and
echolalic responses) or the subjects gave personally conflicting responses
which made them difficult to categorize. Because none of the response categories was appropriate for this type of subject a separate category was made. This category was labeled Distortion and was identified for statistical analyses as a zero.

The response categories which do represent concept levels were numbered consecutively (1 through 6) for statistical analyses. The higher the number the more sophisticated the response. Category 1 had two subcategories; Category 2, one category; and Category 3, three subcategories. The subcategories were divided in this manner in order to distinguish between the quality of abstractions and completeness of responses within Level 3. Level 1 had two subcategories because responses showing curiosity and awareness were distinguished from a complete unawareness concerning death as found in the interview responses. If there was a disagreement between the judgments, the category used was that of the researcher.

Reliability. Reliability of the categorization of responses was tested using an independent judge. The judge selected was 1) a Ph.D. candidate in developmental psychology specializing in developmental disabilities, 2) was familiar with Piaget’s theory and stages of cognitive development, 3) had training and experience with psychological testing and scoring with developmentally disabled adults and children, and 4) was capable of responding to the death concept interview at the most sophisticated level. The judge also had experience with the Klopfer (1954) method of scoring the Rorschach including the conceptual understanding of "form control." Form control was a concept which was useful in examining whether a subject could support his/her statements regarding death or if he/she was merely
verbalizing statements heard, but not comprehended, about death. This judge's knowledge was not thought necessary but made categorization training more efficient and possibly increased the inter-rater reliability level.

Judge training. An initial two hours were spent explaining the study. This was done by briefly summarizing the developmental studies pertinent to this study, integrating Piagetian stages already familiar to the judge and then explaining the mechanics of using the manual and decision chart. Clarification, using sample interviews, was necessary. Difficulties specifically related to the methods used in recording the interview on the recording sheet were identified. No audio tapes were needed by the judge for making the categorizations although they were available. The judge stated following her participation that she felt a transcribed interview could have increased the level of reliability, but would have assisted only in clarifying the qualified responses on the irreversibility and universality questions.

Discussions regarding the categorization judgments occurred on three separate occasions after each set of 5 to 6 judgments. The last fifteen were done without any communications.

Inter-rater Reliability

Thirty of the interviews were randomly selected for the inter-rater reliability study. The results of this study are in Chapter 4.
RESULTS

Introduction

This chapter presents the results of the analyses performed on the data appropriate to the type of variables in the study. Part one of this chapter consists of the descriptive findings of the two samples, persons with developmental disabilities (DD) working in Franklin County Board of Mental Retardation/Developmental Disabilities (FCBM/R/DD) ARC-Industries workshops North and West, and the staff volunteers (SV) working as a maintenance worker, instructor, or rehabilitation specialist at ARC-Industries North and West. Part two of this chapter will present the analyses which test the seven hypotheses for this study. Part three will present the test for animism (Safier Test) results followed by Part four with the analyses of the drawings. The chapter concludes with a description of responses in terms of the concepts universality and irreversibility.

Choice of Analyses

The variable of death categories was assumed to be ordinal. The categories were judged to be equi-distance and did not fit the requirements to be analyzed as an interval variable. Non-parametric statistics were the most appropriate tests for most of this study, with a few exceptions, because they do not assume a normal distribution. Because this is an exploratory study with no support for a normal distribution and because developmentally disabled persons are difficult to defend as fitting a normal distribution, it was felt that parametric statistics were inappropriate. The exceptions to the use of non-parametric statistics were when ANOVA, t-test, or a correlation
test was used. The t-test and ANOVA are considered robust tests which
means exceptions made for the assumptions do not strongly affect the
results. Consequently, for the Wechsler subtests scores analyses and the
AAMD Adaptive Behavior Scale scores, which are both considered interval
variables, ANOVA was the most appropriate choice. A correlation test was
selected as the most appropriate for inter-rater reliability.

Chi-square tests were used when the variables were ordinal and/or
nominal and the expected frequencies were 5 or greater. For the repeated
measures, sign tests were used because the expected frequencies did not
meet the requirements of the McNemar test (expected frequencies were less
than 5).

Interview Reports

During the interview, the DD subjects were asked where they lived.
Seven different kinds of living situations were identified. These seven were
labeled as 1) living at home with a relative other than parents (HO), 2) living
at home with parents (HP), 3) living in a foster home (F), 4) living in an
Association for Developmentally Disabled group home (AG), 5) a group home
other than ADD group home (OG), 6) an institution (I), and 7) other (O). No
person in the sample lived in an institution; however, some lived in the
C.O.R.C. (Central Ohio Rehabilitation Center, previously known as Goodwill)
Dormitory. Table 2 summarizes where persons were living at the time of
their interviews.

Death experience reported. The ages of the DD subjects ranged from
21 to 60 years of age. The ages of the SV ranged from 21 to 40. As age
increased, it would be natural to expect that experiences of death would
also increase. Overall, comparing the SV to the DD sample, it was found that
Table 2
Living Situations by Subject Type

<table>
<thead>
<tr>
<th>Subject Type</th>
<th>Home With Relative Parent(s) n (%)</th>
<th>Home With Foster Parent(s) n (%)</th>
<th>A.D.D. Group Home n (%)</th>
<th>Other Group Home n (%)</th>
<th>Other Staff n (%)</th>
<th>Other Volunteers n (%)</th>
<th>Total n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmentally Disabled n=48</td>
<td>6 (13)</td>
<td>13 (27)</td>
<td>1 (2)</td>
<td>11 (23)</td>
<td>9 (19)</td>
<td>8 (17)</td>
<td>48 (100)</td>
</tr>
<tr>
<td>Staff Volunteers n=20</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>20 (100)</td>
</tr>
<tr>
<td>Total</td>
<td>6 (9)</td>
<td>13 (19)</td>
<td>1 (2)</td>
<td>11 (16)</td>
<td>9 (13)</td>
<td>28 (41)</td>
<td>68 (100)</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 35.33, df = 5, p < .01. \] (living situations were found different for the subject type: DD&SV)

\[ ^bC.O.R.C. \] Dormitory, independent apartment, apartment in friends' home, or own home.
the DD sample reported having had more experience with deaths of relatives and friends. Table 3 summarizes death experience as reported in both samples. Mothers had died significantly more often in the DD sample than in the SV sample (chi-square = 4.68, df = 1, p < .05). The SV reported having had experienced death of an animal more often than had the DD sample. All but one SV member (95%) reported deaths of at least one animal while only 34 (71%) of the DD’s reported experiencing a death of an animal (more SV experienced death of animals than DD: chi-square = 4.20, df = 1, p < .05).

Chi-square tests were done to assess the relationship of age to the reported deaths of relatives and an animal. Table 4 summarizes the results. Age level (21-39 and 40-60) was found to be significantly related to the number of deaths reported for mother (older DD subjects had experienced more deaths of mothers than younger DD subjects: chi-square = 12.22, df = 1, p < .001), and father (older DD subjects had experienced deaths of fathers more than younger DD subjects: chi-square = 15.78, df = 1, p < .001). Younger subjects reported more deaths of grandparents. Younger DD subjects reported more deaths of grandmothers than older DD subjects: chi-square = 8.21, df = 1, p < .01). Younger DD subjects also reported more deaths of grandfathers than older DD subjects: chi-square = 5.26, df = 1, p < .05). No other relative or animal was found to be significant for the age of subject.

Verification of Death Experiences. A questionnaire accompanied by an explanatory letter was sent home with each person who agreed to participate in the study (See Appendix B for the questionnaire and letter). The questionnaire was to be completed by a knowledgeable person at the subject’s residence in order that the subject’s self report could be verified. Two subjects (both at A R C-Industries North) indicated that there was no one
Table 3

Reported Deaths of Relatives, Friends and Animals

<table>
<thead>
<tr>
<th>Subject Type</th>
<th>Mother</th>
<th>Father</th>
<th>Grandmother</th>
<th>Grandfather</th>
<th>Brother</th>
<th>Sister</th>
<th>Aunt</th>
<th>Uncle</th>
<th>Other Animal</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmentally</td>
<td>n=48</td>
<td>18 (38)</td>
<td>22 (46)</td>
<td>20 (42)</td>
<td>6 (13)</td>
<td>3 (6)</td>
<td>12 (25)</td>
<td>12 (25)</td>
<td>15 (31)</td>
<td>34 (71)</td>
</tr>
<tr>
<td>Disabled</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff Volunteers</td>
<td>n=20</td>
<td>2 (10)</td>
<td>4 (20)</td>
<td>8 (40)</td>
<td>12 (60)</td>
<td>0 (0)</td>
<td>7 (35)</td>
<td>8 (40)</td>
<td>7 (35)</td>
<td>19 (95)</td>
</tr>
<tr>
<td>Total</td>
<td>20 (29)</td>
<td>26 (38)</td>
<td>28 (41)</td>
<td>32 (47)</td>
<td>6 (9)</td>
<td>3 (4)</td>
<td>19 (28)</td>
<td>20 (29)</td>
<td>22 (32)</td>
<td>53 (78)</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 4.68, df=1, p < .05 \text{ (proportionally more DD subjects reported deaths of mothers than SV subjects).} \]

\[ \chi^2 = 4.20, df=1, p < .05 \text{ (proportionally more SV subjects reported deaths of animals than DD subjects).} \]
Table 4
Reported Relative Deaths by Age of DD Sample

<table>
<thead>
<tr>
<th>Age Level</th>
<th>Mother</th>
<th>Father</th>
<th>Grandmother</th>
<th>Grandfather</th>
<th>Brother</th>
<th>Sister</th>
<th>Aunt</th>
<th>Uncle</th>
<th>Other</th>
<th>Animal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Young 21-39</td>
<td>n = 24</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 (13)</td>
<td>4 (17)</td>
<td>15 (58)</td>
<td>14 (17)</td>
<td>4 (17)</td>
<td>3 (13)</td>
<td>6 (25)</td>
<td>8 (33)</td>
<td>18 (75)</td>
<td></td>
</tr>
<tr>
<td>Middle Age</td>
<td>n = 24</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>15 (63)</td>
<td>18 (75)</td>
<td>5 (21)</td>
<td>6 (25)</td>
<td>2 (8)</td>
<td>0 (0)</td>
<td>8 (33)</td>
<td>6 (25)</td>
<td>7 (29)</td>
<td>16 (67)</td>
</tr>
<tr>
<td>Total n = 48</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>18 (38)</td>
<td>22 (46)</td>
<td>20 (42)</td>
<td>20 (42)</td>
<td>6 (13)</td>
<td>3 (6)</td>
<td>12 (25)</td>
<td>12 (25)</td>
<td>15 (31)</td>
<td>34 (71)</td>
</tr>
</tbody>
</table>

\(^a\chi^2 = 12.22, \text{df} = 1, p < .001.\) (more Middle Age Subjects reported deaths of their mother).

\(^b\chi^2 = 15.78, \text{df} = 1, p < .001.\) (more Middle Age Subjects reported deaths of their father).

\(^c\chi^2 = 8.21, \text{df} = 1, p < .01.\) (more Young Subjects reported deaths of their grandmother).

\(^d\chi^2 = 5.25, \text{df} = 1, p < .05.\) (more Young Subjects reported deaths of their grandfather).
at home to fill out the questionnaire (i.e., lived independently). A total of 35 questionnaires were returned. Of those returned, 4 questionnaires were returned stating that persons at the subjects' home (all were parents) did not want the developmentally disabled person to participate. One additional person, returning a questionnaire, refused to participate at the time she was to be interviewed even though she had initially agreed to participate and had signed a consent form. All requests by parents asking to not have their son/daughter participate (even when the person was his/her own guardian) were respected. One person who lived in a private group home returned a note from her "house mother" stating that the house mother did not want the woman interviewed. However, this individual insisted on being interviewed; therefore, this questionnaire was not counted in the refusing category. Sixty-five percent (30 out of 46) of the subject's responses were verified at some level by a questionnaire returned by a person at home. Of the questionnaires returned, 90% verified the deaths reported (3 subjects were not correct; i.e., deaths had occurred for relatives to subjects reporting that he/she had no relatives or friends who had died). Both the subjects and the persons who filled out the questionnaire were frequently unsure of the length of time since the deaths if the death had occurred more than 5 years previously. Since the effects of length of time since death were not assessed statistically, the accuracy of these reports was only considered for report verification. Subjects who lived with non-relatives (i.e., group home residents) often had more facts and information than the informant filling out the questionnaires. Because the information for these persons was at least partially verified, all the information given by those subjects was
assumed to be correct. All statistical analyses for death experiences used the subjects' reports.

No attempt was made to verify reports of staff volunteers.

Wechsler Adult Intelligence Scale Subtests. All subjects were given the Wechsler Adult Intelligence Scale (WAIS) Vocabulary and Similarities subtests as a quick way of assessing 1) verbal concept formation, 2) abstract reasoning, 3) verifying general intellectual functioning level, and to 4) establish that SV represented a different population. Scaled scores were computed. Both scores were added together for a total score. This total was recorded for each subject. The DD sample scored from 0-15. The SV sample scored from 19-36. The samples were found to be different in their scores. The SV sample was higher than the DD sample ($t = 5.81$, $df = 66$, $p < .001$).

Figure 1 is a bar graph showing the frequency distribution of the scores.

Test-Retest Results

As previously discussed in Chapter 3, a repeated interview was designed to examine what kind, if any, changes would occur for persons repeating the interview. Since unexpected changes had occurred in the pilot study. Twenty-six (26) subjects were given the same interview twice. A total of 16 subjects were randomly drawn through a chance selection from the original DD sample, 8 from each workshop. A total of 10 subjects were randomly selected from the original SV with 5 from each workshop. Tests were done to insure that there had been no significant misrepresentation for age, sex and intelligence level. No significant differences were found. The purpose for repeating the interview was to assess whether changes occurred in the group as a whole and if there were any differences in this respect between the two populations.
Number of Subjects

<table>
<thead>
<tr>
<th>DD Sample</th>
<th>mean=6.19</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=48</td>
<td>S.D.=16.43</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SV Sample</th>
<th>mean=27.95</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=20</td>
<td>S.D.=4.42</td>
</tr>
</tbody>
</table>

Figure 1. Scores for Wechsler Adult Intelligence Scale Vocabulary plus Similarities Subtests
A two-way ANOVA was performed on these WAIS scores to test the difference between the DD and the SV samples and to determine whether scores were different at the two administrations of the test. Table 5 presents the results on the dependent variable of the WAIS subtests scores.

An examination of Table 5 shows that there was a significant difference between DD and SV subjects on the WAIS subtests scores at \( p < .001 \). The WAIS subtests scores were found to be stable in terms of repeating the interview.

**Do you ever think about Death?** In the pilot study, 25% of the subjects (2 out of 8) changed their answer from a yes to a no in response to the question, "Do you ever think about death?" It was judged important to make this comparison in a larger sample.

Similar changes occurred in the larger DD sample in responses to the question, "Do you ever think about death?" Four of the sixteen subjects taking the interview twice changed their responses. However, test for change indicates that the null hypothesis cannot be rejected at the .01 level. \( (H_0: \ 1/2 \text{ change}, \ 1/2 \text{ stay same}; \ p < .038) \). Table 6 summarizes the results. Fewer people acknowledged thoughts about death at the second interview, a pattern also observed in the pilot study.

**Death Category.** Relations between interviews for the death categories were tested using the Spearman Rank Order Test. The DD subjects (n=16) death categories between the first and second interviews were highly correlated \( (r = .871, \ p < .01) \). The SV subjects (n=10) death categories between the first and second interviews were also highly correlated \( (r = .745, \ p < .05) \). When death categories of both subject types were analyzed as a total group,
Table 5

Summary of ANOVA on the WAIS Subtests for Subject Type and Repeated Interview

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subject Type</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DD-SV</td>
<td>5299.23</td>
<td>1</td>
<td>5299.23</td>
<td>156.97</td>
<td>0.000</td>
</tr>
<tr>
<td>Error</td>
<td>810.25</td>
<td>24</td>
<td>33.76</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Repeated Interview</td>
<td>0.19</td>
<td>1</td>
<td>0.19</td>
<td>-0.08</td>
<td>N.S.</td>
</tr>
<tr>
<td>Error</td>
<td>59.75</td>
<td>24</td>
<td>2.49</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 6

Responses to "Do you ever think about death?"
Between Interviews One and Two

<table>
<thead>
<tr>
<th>Subject Type/Answer</th>
<th>First Interview</th>
<th>Second Interview</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n   (%)</td>
<td>n   (%)</td>
<td>n   (%)</td>
</tr>
<tr>
<td>DD Yes</td>
<td>11 (69)</td>
<td>7 (44)</td>
<td>18 (56)</td>
</tr>
<tr>
<td>DD No</td>
<td>5 (31)</td>
<td>9 (56)</td>
<td>14 (44)</td>
</tr>
<tr>
<td>SV Yes</td>
<td>10 (100)</td>
<td>9 (90)</td>
<td>19 (80)</td>
</tr>
<tr>
<td>SV No</td>
<td>0 (0)</td>
<td>1 (10)</td>
<td>1 (20)</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
<td>26</td>
<td>52</td>
</tr>
</tbody>
</table>

DD=Developmentally Disabled Sample, n=16.
Staff=Staff Volunteer Sample, n=10.
the relation between the two interviews was also found to be significantly related ($r = .947, p<.01$).

Other Changes Between Interviews. Reports of experiences of deaths for relatives, friends and/or animals between the first and second interviews were tested with the sign test. Changes were found in both groups for the variables grandmother and grandfather. Other changes were found in the variables aunt, uncle, animal in at least one of the samples. A significant number of subjects changed for the DD subjects' reports for grandmother deaths (7 changed from no to yes, 2 changed from yes to no). Similarly, SV subjects' reports changed for grandmother deaths (2 changed from no to yes, 1 changed from yes to no). Both groups also reported changes in deaths of grandfathers between interview one and two. The DD sample had 7 subjects change responses from no to yes and 3 changed from yes to no for grandfather deaths. The SV sample had 3 persons who changed their responses from no to yes for the grandfather variable. A significant number of SV subjects' reports changed regarding the death of an aunt in the second interview (2 changed from no to yes. Note: one subject stated that an aunt had died in the time between her interviews). DD subjects reported fewer deaths of an uncle for the second interview than the first (5 subjects changed from yes to no). DD subjects had changes in reports for death of animals between interviews (5 subjects changed from no to yes). The DD subjects also had changes for the "other" variable (included cousins, and close friends and acquaintances). Four DD subjects changed from yes to no for the "other" variable.

These results indicate that there is a problem regarding the reliability of the reported deaths of relatives in both samples but the lack of
consistency is somewhat higher in the DD sample. This finding indicates that the reported deaths of relatives be accepted with caution. Because the other parts of the interview were found to not change, those results can be presumed to include less error. Based on the subjects' abilities to describe deaths which they had observed, it would seem that the error in reporting is not that the subjects had or had not experienced a death of a relative, but rather the accuracy of the relationship "label" (grandmother, grandfather).

The questions were also posed to require a yes or no response which has also been observed to illicit more opportunity of changes in response when the DD person does not fully understand what is being requested of him/her.

The significance level for the variables which were compared for changes between interviews are summarized in Table 7 by subject type.

**Hypotheses Test Results**

All data discussed in this portion of the chapter are presented and discussed according to the hypotheses posed for this study. The following predicted hypotheses were formulated:

1) Responses given by persons who are developmentally disabled can be reliably categorized into death categories.

2) There is a relationship ($p<.05$) between the previously measured level of intellectual functioning of the subjects and the death categories.

3) There is no relationship between sex of the subjects and the death categories.

4) There is no relationship between the workshop attended by the subjects and the death categories.

5) There is no relationship between age of subjects and the death categories.
Table 7
Changes In Responses Between Interviews

<table>
<thead>
<tr>
<th>Variables</th>
<th>Type of Subjects</th>
<th># of Persons Changing</th>
<th>Sign test</th>
<th>Significance Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Think about Death</td>
<td>DO</td>
<td>16</td>
<td></td>
<td>.038</td>
</tr>
<tr>
<td>Think about Death</td>
<td>SV</td>
<td>10</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td>Think about Death</td>
<td>Both</td>
<td>26</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td>Mother</td>
<td>DO</td>
<td>16</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td>Mother</td>
<td>SV</td>
<td>10</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td>Mother</td>
<td>Both</td>
<td>26</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td>Father</td>
<td>DO</td>
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<td></td>
<td>.001</td>
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<tr>
<td>Father</td>
<td>SV</td>
<td>10</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td>Father</td>
<td>Both</td>
<td>26</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td>Grandmother</td>
<td>DO</td>
<td>16</td>
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<td>.773</td>
</tr>
<tr>
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<td>SV</td>
<td>10</td>
<td></td>
<td>.172</td>
</tr>
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<td>Grandmother</td>
<td>Both</td>
<td>26</td>
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<td>.488</td>
</tr>
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<td>Grandfather</td>
<td>DO</td>
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<td>.172</td>
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<td>Grandfather</td>
<td>Both</td>
<td>26</td>
<td></td>
<td>.500</td>
</tr>
<tr>
<td>Brother</td>
<td>DO</td>
<td>16</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td>Brother</td>
<td>SV</td>
<td>10</td>
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<tr>
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<td>Both</td>
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<td></td>
<td>.001</td>
</tr>
<tr>
<td>Sister</td>
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<td>16</td>
<td></td>
<td>.011</td>
</tr>
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<td>Sister</td>
<td>SV</td>
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<td>.001</td>
</tr>
<tr>
<td>Sister</td>
<td>Both</td>
<td>26</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td>Aunt</td>
<td>DO</td>
<td>16</td>
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<td>.011</td>
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<td>SV</td>
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<td>Both</td>
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<td>Uncle</td>
<td>Both</td>
<td>26</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td>Animal</td>
<td>DO</td>
<td>16</td>
<td></td>
<td>.105</td>
</tr>
<tr>
<td>Animal</td>
<td>SV</td>
<td>10</td>
<td></td>
<td>.011</td>
</tr>
<tr>
<td>Animal</td>
<td>Both</td>
<td>26</td>
<td></td>
<td>.003</td>
</tr>
<tr>
<td>Other</td>
<td>DO</td>
<td>16</td>
<td></td>
<td>.038</td>
</tr>
<tr>
<td>Other</td>
<td>SV</td>
<td>10</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td>Other</td>
<td>Both</td>
<td>26</td>
<td></td>
<td>.001</td>
</tr>
</tbody>
</table>

* Small sample, \( N < 25 \) performed binomial test

** Large sample, \( N > 25 \) performed \( z \)-transformation
6) There is a relationship between the measured adaptive behavior of subjects and the death categories.

7) Responses given by persons who are developmentally disabled are different from those given by workshop staff with respect to death categories.

The first hypothesis tested states: Responses given by persons who are developmentally disabled can be reliably categorized into death categories.

Two judges rated thirty randomly selected interviews. Inter-rater reliability was quite high (r = .937 p<.01). Judges agreed completely on 80% of their category judgments. Therefore, the predicted hypothesis is accepted.

The second hypothesis tested states: There is a relationship (p<.05) between the previously measured level of intellectual functioning of the subjects and the sophistication of understanding of death as revealed by answers in the structured interview (death categories).

Significant differences between the intellectual level using the entire range of death categories (0–6: Distortion, Categories 1a, 1b, 2, 3a, 3b, 3c) were found (subjects who were intellectually functioning at Level I had more sophisticated death categories than Level II subjects: chi-square = 15.56, df = 6, p<.05). Because there were so few subjects in the Distortion, 1a and 1b categories, a better analysis was done by collapsing the categories so that there were no subcategories. The resulting categories were Categories 1, 2, and 3. Significant differences were found using these collapsed categories. The higher intellectual functioning level (Level I) also had the higher death categories (chi-square = 14.44, df = 3, p<.01). The observed frequencies for the categories by intelligence level is presented in Table 8. The predicted hypothesis is accepted.
The third hypothesis tested states: There is no relationship between sex of the subjects and the death categories. The test for this hypothesis was done with collapsed and original death categories. Significant sex differences were not found with either the 6 original categories or the 3 collapsed categories (chi-square = 3.58, df = 6, N.S.; collapsed categories chi-square = 0.80, df = 3, N.S.). The predicted hypothesis is accepted. Table 9 summarizes the observed frequencies of responses given by male and female subjects.

The fourth hypothesis tested states: There is no relationship between the geographic location of workshop attended (North and West) by the subject and the death categories. No significant differences were found (chi-square = 7.71, df = 6, N.S.) Once again, as in the second hypothesis, a test using totals for only the 3 main categories was done (labeled collapsed categories). The analysis with collapsed categories found no difference for workshop in death categories (chi-square = 3.68, df = 3, N.S.). The predicted hypothesis is accepted. Table 10 summarizes the observed frequencies of subjects' death categories from the North and West workshops.

The fifth hypothesis tested states: There is no relationship between the age of subjects and the death categories. The differences were not significant. No difference for age groups of DD subjects for analysis without and with collapsed categories (all death categories chi-square = 4.61, df = 6, N.S.; collapsed death categories chi-square = 2.21, df = 3, N.S.). The predicted hypothesis is accepted. Table 11 summarizes the observed frequencies of the DD subjects' death categories by the two age levels.

The sixth hypothesis tested states: There is a relationship between measured adaptive behavior of DD subjects and the death categories. For the
Table 8

Death Category by Intellectual Level

<table>
<thead>
<tr>
<th>Intell. Level</th>
<th>Distortion</th>
<th>1a (%)</th>
<th>1b (%)</th>
<th>2 (%)</th>
<th>3a (%)</th>
<th>3b (%)</th>
<th>3c (%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>1 (4)</td>
<td>(0)</td>
<td>(0)</td>
<td>1 (29)</td>
<td>8 (33)</td>
<td>7 (29)</td>
<td>1 (4)</td>
<td>24</td>
</tr>
<tr>
<td>II</td>
<td>1 (4)</td>
<td>1 (4)</td>
<td>1 (4)</td>
<td>1 (4)</td>
<td>18 (75)</td>
<td>2 (8)</td>
<td>1 (4)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Total</td>
<td>2 (4)</td>
<td>1 (2)</td>
<td>1 (2)</td>
<td>25 (52)</td>
<td>10 (21)</td>
<td>8 (17)</td>
<td>1 (2)</td>
<td>48</td>
</tr>
</tbody>
</table>

* 15.56, df=6, $p<.05$. (Level I Death Categories were higher than Level II).

Table 9

Death Category by Sex of Developmentally Disabled Subjects

<table>
<thead>
<tr>
<th>Sex of Subject</th>
<th>Distortion</th>
<th>1a (%)</th>
<th>1b (%)</th>
<th>2 (%)</th>
<th>3a (%)</th>
<th>3b (%)</th>
<th>3c (%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>1 (4)</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>11 (46)</td>
<td>5 (21)</td>
<td>5 (21)</td>
<td>1 (4)</td>
<td>24</td>
</tr>
<tr>
<td>Females</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>1 (4)</td>
<td>14 (58)</td>
<td>5 (21)</td>
<td>3 (13)</td>
<td>0 (0)</td>
<td>24</td>
</tr>
<tr>
<td>Total</td>
<td>2 (4)</td>
<td>1 (2)</td>
<td>1 (2)</td>
<td>25 (52)</td>
<td>10 (21)</td>
<td>8 (17)</td>
<td>1 (2)</td>
<td>48</td>
</tr>
</tbody>
</table>

Table 10

Death Category by Workshop Attended for Developmentally Disabled Subjects

<table>
<thead>
<tr>
<th>Workshop Attended</th>
<th>Distortion</th>
<th>1a (%)</th>
<th>1b (%)</th>
<th>2 (%)</th>
<th>3a (%)</th>
<th>3b (%)</th>
<th>3c (%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>North</td>
<td>2 (8)</td>
<td>1 (4)</td>
<td>1 (4)</td>
<td>10 (42)</td>
<td>7 (29)</td>
<td>3 (13)</td>
<td>0 (0)</td>
<td>24</td>
</tr>
<tr>
<td>West</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>15 (63)</td>
<td>3 (13)</td>
<td>5 (21)</td>
<td>1 (4)</td>
<td>24</td>
</tr>
<tr>
<td>Total</td>
<td>2 (4)</td>
<td>1 (2)</td>
<td>1 (2)</td>
<td>25 (52)</td>
<td>10 (21)</td>
<td>9 (17)</td>
<td>1 (2)</td>
<td>48</td>
</tr>
</tbody>
</table>
Table 11
Death Category by Age Group of DD Subjects

<table>
<thead>
<tr>
<th>Age of DD Subjects</th>
<th>Distortion</th>
<th>1a</th>
<th>1b</th>
<th>2</th>
<th>3a</th>
<th>3b</th>
<th>3c</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>21-39</td>
<td>1 (4)</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>15 (63)</td>
<td>4 (17)</td>
<td>3 (13)</td>
<td>0 (0)</td>
<td>24</td>
</tr>
<tr>
<td>40-60</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>1 (4)</td>
<td>10 (42)</td>
<td>6 (25)</td>
<td>5 (21)</td>
<td>1 (4)</td>
<td>24</td>
</tr>
<tr>
<td>Total</td>
<td>2 (4)</td>
<td>1 (2)</td>
<td>1 (2)</td>
<td>25 (52)</td>
<td>10 (21)</td>
<td>8 (17)</td>
<td>1 (2)</td>
<td>48</td>
</tr>
</tbody>
</table>
purpose of this study, adaptive behavior was assessed using the AAMD Adaptive Behavior Scale (Nihira et al., 1974). In order to keep the scale criteria based and to be able to compare across age levels, raw scores were used. In addition, because the sample size is small, some domain scores which have been reported with similar groupings in clinical practice (Leland, Shoae, & Vayda, 1975), were added together to decrease the number of domains. Scores from domains with low frequency maladaptive behaviors were also added together; e.g., Manners and Habits. The following were the domains which were added together and the resulting analysis unit label:

1) Independent Functioning plus Domestic Activity=
   Personal Independence, \textit{ABS}_1

2) Economic Activity plus Language Development plus Numbers and Time=
   Cognitive Triad, \textit{ABS}_2.

3) Responsibility plus Socialization=
   Social-Motivation, \textit{ABS}_3.

4) Vocational=
   Vocational, \textit{ABS}_4.

5) Self-Direction=
   Self-Direction, \textit{ABS}_5.

6) Violent and Destructive Behavior=

7) Antisocial Behavior=

8) Rebellious Behavior=
   Rebellious, \textit{ABS}_8.

9) Untrustworthy=

10) Withdrawal=
    Withdrawal, \textit{ABS}_{10}.

11) Stereotyped Behavior and Odd Mannerism plus Inappropriate
    Interpersonal Manners=
    Mannerisms/Manners, \textit{ABS}_{11}.
12) Unacceptable Vocal Habits plus Unacceptable or Eccentric Habits = \textit{Habits, ABS}_{12}.


14) Hyperactive Tendencies = \textit{Hyperactive Tendencies, ABS}_{14}.

15) Psychological Disturbances = \textit{Psychological Disturbances, ABS}_{15}.

One subject refused to allow his adaptive behavior assessment to be obtained for this study. (This subject was judged to be in the "Distortion" category.) Because there were so few subjects judged "Distortion," it was decided that the other subject in the "Distortion" category would also be dropped and the death categories would be collapsed. Categories 1, 2, and 3 were the categories used for the analyses. The one-way ANOVAS on the 15 ABS variables by Death Category found significant differences for the Personal Independence (the higher death category subjects also had higher scores for the ABS\textsubscript{1} variable: $F = 3.56$, $df = 2$, $p < .05$) and Cognitive Triad (the higher death category subjects also had higher scores for the ABS\textsubscript{2} variable: $F = 5.07$, $df = 2$, $p < .01$). No other significant differences were found. In terms of these results, the predicted hypothesis is accepted. Table 12 summarizes the results.

The \textbf{seventh hypothesis} tested states: Death categorization based on responses given by the persons who are developmentally disabled will be different from those of workshop staff volunteers. The difference between groups was significant (SV subjects had higher death categories than DD subjects: chi-square = 50.81, $df = 6$, $p < .01$). Table 13 summarizes the frequencies of the categories by the type of subject. The predicted hypothesis 7 is accepted.
Table 12
Summary of One-Way ANOVAS on ABS Variables by Death Category

<table>
<thead>
<tr>
<th>Dependent Variable/ABS Measures</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABS_1</td>
<td>503.35</td>
<td>2</td>
<td>251.67</td>
<td>3.56</td>
<td>0.04</td>
</tr>
<tr>
<td>ABS_2</td>
<td>965.52</td>
<td>2</td>
<td>482.76</td>
<td>5.07</td>
<td>0.01</td>
</tr>
<tr>
<td>ABS_3</td>
<td>56.66</td>
<td>2</td>
<td>28.68</td>
<td>2.55</td>
<td>N.S.</td>
</tr>
<tr>
<td>ABS_4</td>
<td>2.33</td>
<td>2</td>
<td>1.16</td>
<td>0.63</td>
<td>N.S.</td>
</tr>
<tr>
<td>ABS_5</td>
<td>6.85</td>
<td>2</td>
<td>3.42</td>
<td>0.98</td>
<td>N.S.</td>
</tr>
<tr>
<td>ABS_6</td>
<td>1.93</td>
<td>2</td>
<td>0.96</td>
<td>0.75</td>
<td>N.S.</td>
</tr>
<tr>
<td>ABS_7</td>
<td>26.68</td>
<td>2</td>
<td>13.34</td>
<td>0.88</td>
<td>N.S.</td>
</tr>
<tr>
<td>ABS_8</td>
<td>2.21</td>
<td>2</td>
<td>1.10</td>
<td>0.08</td>
<td>N.S.</td>
</tr>
<tr>
<td>ABS_9</td>
<td>0.96</td>
<td>2</td>
<td>0.48</td>
<td>0.23</td>
<td>N.S.</td>
</tr>
<tr>
<td>ABS_10</td>
<td>43.17</td>
<td>2</td>
<td>21.58</td>
<td>3.03</td>
<td>N.S.</td>
</tr>
<tr>
<td>ABS_11</td>
<td>0.43</td>
<td>2</td>
<td>0.22</td>
<td>0.16</td>
<td>N.S.</td>
</tr>
<tr>
<td>ABS_12</td>
<td>0.09</td>
<td>2</td>
<td>0.05</td>
<td>0.01</td>
<td>N.S.</td>
</tr>
<tr>
<td>ABS_13</td>
<td>0.09</td>
<td>2</td>
<td>0.05</td>
<td>0.09</td>
<td>N.S.</td>
</tr>
<tr>
<td>ABS_14</td>
<td>0.05</td>
<td>2</td>
<td>0.02</td>
<td>0.11</td>
<td>N.S.</td>
</tr>
<tr>
<td>ABS_15</td>
<td>4.09</td>
<td>2</td>
<td>2.05</td>
<td>0.08</td>
<td>N.S.</td>
</tr>
</tbody>
</table>
Table 13
Death Categories

<table>
<thead>
<tr>
<th>Subject Type</th>
<th>Distortion</th>
<th>Category</th>
<th>n</th>
<th>(1)</th>
<th>(2)</th>
<th>(3a)</th>
<th>(3b)</th>
<th>(3c)</th>
<th>Total</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmentally Disabled</td>
<td>2</td>
<td>(4)</td>
<td>1</td>
<td>(2)</td>
<td>(2)</td>
<td>25</td>
<td>(52)</td>
<td>10</td>
<td>(21)</td>
<td>8</td>
</tr>
<tr>
<td>Staff Volunteers</td>
<td>0</td>
<td>(0)</td>
<td>0</td>
<td>(0)</td>
<td>0</td>
<td>(0)</td>
<td>0</td>
<td>1</td>
<td>(5)</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>2</td>
<td>(3)</td>
<td>1</td>
<td>(1)</td>
<td>1</td>
<td>(1)</td>
<td>25</td>
<td>(53)</td>
<td>11</td>
<td>(16)</td>
</tr>
</tbody>
</table>

$^a Z^2=50.81, df=6, p<.01$. (Death Categories were lower for Developmentally Disabled than for Staff Volunteers).

Table 14
Responses to the Question, "Do you ever think about death?"

<table>
<thead>
<tr>
<th>Subject Type</th>
<th>Yes</th>
<th>(4)</th>
<th>No</th>
<th>(4)</th>
<th>Total</th>
<th>(4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmentally Disabled</td>
<td>27</td>
<td>(56)</td>
<td>21</td>
<td>(44)</td>
<td>48</td>
<td>(100)</td>
</tr>
<tr>
<td>Staff Volunteers</td>
<td>20</td>
<td>(100)</td>
<td>0</td>
<td>(0)</td>
<td>20</td>
<td>(100)</td>
</tr>
<tr>
<td>Total</td>
<td>47</td>
<td>(69)</td>
<td>21</td>
<td>(31)</td>
<td>68</td>
<td>(100)</td>
</tr>
</tbody>
</table>

$^a Z^2=11.75, df=1, p<.01$. (Affirmative responses to this question were lower for Developmentally Disabled than for the Staff Volunteers).
Awareness Level of Thoughts About Death

There were other findings in this study which were explored without the use of hypotheses. Many finds were related to differences between the subjects types (DD and SV). Some of these have already been discussed particularly in living situation and death experience reports differences between the first and second interview. Acknowledgement or awareness of thoughts about death was also found to be significantly different. Proportionally more SV subjects responded affirmatively to the question, "Do you ever think about death?" than DD subjects (chi-square = 11.75, df = 1, p<.01). Table 14 summarizes the observed frequencies for the two groups.

Safier Test

A part of the interview was used to assess the concept "animism". For reference purposes, this was labeled the Safier Test since part of her word list and the sequence of questions were used. The judged death categories did not use the results of the Safier Test since Safier (1964) reported that animism is similar to but separate from the death concept.

The Safier Test was made by inserting words from a list of objects inserted into four questions. The object list used for the present study was a dog, ball, tree, boy, moon, and cloud. The questions were:

1) Does a ______ live?, Is a ______ living?
2) Does a ______ hurt when hit?
3) Does a ______ grow up?
4) Does a ______ die?

The analysis compared wrong responses between the two samples. Table 15 is a summary table for observed frequencies of answers for each object, question and type of subject. The DD and the SV groups were not different
Table 15
Answers on Safer Test by Type of Subject

<table>
<thead>
<tr>
<th>Subject Type/Answers</th>
<th>OGQ Questions</th>
<th>BALL Questions</th>
<th>TREE Questions</th>
<th>BOY Questions</th>
<th>MOON Questions</th>
<th>CLOUD Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. 2. 3. 4. 1. 2. 3. 4. 1. 2. 3. 4. 1. 2. 3. 4. 1. 2. 3. 4. 1. 2. 3. 4. 1. 2. 3. 4.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OD Subjects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>41 40 46 41 20 19 15 11</td>
<td>37 21 42 35 46 41 48 43 32</td>
<td>17 24 16 30 16 24 15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>(65) (63) (65) (42) (40) (31) (31) (31)</td>
<td>(77) (44) (65) (73) (96) (85) (100) (90) (67) (35) (50) (31) (63) (31) (50) (31)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>6 8 1 6 28 29 32 36</td>
<td>9 26 6 13 2 7 0 5</td>
<td>12 27 19 30 14 31 22 32</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>(13) (17) (2) (13) (50) (40) (67) (75) (19) (54) (13) (27) (4) (15) (0) (10) (25) (56) (40) (63) (29) (65) (46) (67)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t Know</td>
<td>0 0 0 0 0 0 1 0</td>
<td>1 1 0 0 0 0</td>
<td>4 4 4 2 4 1 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>(0) (0) (0) (0) (0) (0) (2) (0) (2) (2) (0) (0) (0) (0) (0) (0) (0) (8) (8) (8) (4) (8) (2) (2) (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1 0 1 1 1 0 0 1 1 1 0 0 0 0 0 0 1 0 0 0 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>(2) (0) (2) (2) (0) (0) (0) (2) (2) (0) (0) (0) (0) (0) (0) (0) (0) (0) (0) (0) (0) (0) (2) (0) (0) (2) (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SV Subjects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>20 20 20 20 0 0 1 1 20 10 20 20 20 20 20 20 3 1 2 4 3 1 3 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>(100) (100) (100) (100) (0) (0) (5) (5) (100) (50) (100) (100) (100) (100) (100) (100) (100) (15) (5) (10) (20) (15) (5) (15) (15)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0 0 0 0 20 19 19 19 0 5 0 0 0 0 0 0 17 18 18 15 16 19 16 16</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>(0) (0) (0) (0) (100) (95) (95) (95) (0) (25) (0) (0) (0) (0) (0) (0) (0) (85) (90) (90) (75) (33) (40) (33) (33)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t Know</td>
<td>0 0 0 0 0 0 1 0 0 0 4 0 0 0 0 0 0 1 0 0 0 0 0 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>(0) (0) (0) (0) (0) (5) (0) (0) (0) (20) (0) (0) (0) (0) (0) (0) (0) (0) (5) (0) (0) (0) (0) (0) (0)</td>
<td></td>
<td></td>
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<tr>
<td>Other</td>
<td>0 0 0 0 0 0 0 0 0 1 0 0 0 0 0 0 1 0 1 1</td>
<td></td>
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<tr>
<td>%</td>
<td>(0) (0) (0) (0) (0) (0) (0) (0) (0) (5) (0) (0) (0) (0) (0) (0) (0) (0) (5) (0) (0) (0) (5) (5) (5)</td>
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<tr>
<td>Total</td>
<td>68 68 68 68 68 68 68 68 68 68 68 68 68 68 68 68 68 68 68</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

\(^a\chi^2_p < .05\). (Proportionally more SV subjects had correct answers than OD subjects).

\(^b\chi^2_p < .01\). (Proportionally more SV subjects had correct answers than OD subjects.).
for "dog" and "boy" (due to giving correct responses). There were significant differences for "Is a ball alive?" (proportionally more SV than DD subjects answered correctly: chi-square = 10.90, df = 1, p<0.01), "Does a ball hurt when hit?", (proportionally more SV than DD subjects answered correctly: chi-square = 11.31, df = 2, p<0.01), "Is the moon alive?", (proportionally more SV than DD subjects answered correctly: chi-square = 19.36, df =2, p<0.01), "Does the moon grow up?" (proportionally more SV than DD subjects answered correctly: chi-square = 12.68, df = 3, p<0.01), "Is a cloud alive?", (proportionally more SV than DD subjects answered correctly: chi-square = 16.94, df = 3, p<0.01). There were also significant differences for the questions, "Does a tree hurt when hit?", (proportionally more SV than DD subjects answered correctly: chi-square = 10.22, df = 3, p<0.05), "Does a tree die?" (proportionally more SV than DD subjects answered correctly: chi-square = 5.82, df = 1, p<0.05), and "Does the moon hurt when hit?" (proportionally more SV than DD subjects answered correctly: chi-square = 6.74, df = 2, p<0.05).

Animism score compared to Death Category. All subjects interviewed the first time (both DD and SV subjects) were given an "animism" score using the same scoring system reported by Safier (1964). The score was derived by adding all responses which were wrong. The higher the animism score the lower the stage of development. The relationship between the "animism score" and the "death category" score was quite high for both samples using Pearson's Product Moment Correlation. The relationships between the two scores, animism and death category, were significant (DD sample, r = -0.457; SV sample, r = -0.472).
Drawing Analyses

All subjects were asked to "draw death" after completing the two Wechsler Adult Intelligence Scale subtests. The subjects were each given one sheet of white paper 8 1/2" x 11" and eight different colors (red, green, blue, yellow, brown, black, purple) of water colored felt tip pens with which to draw. After the "death" drawing was completed each subject was asked about the drawing. After the verbal portion of the interview was completed, the subject was again asked to draw. This time, the subject was asked to draw anything he/she would like to draw. Analyses were done regarding the drawings including: 1) a list of descriptions of the death drawings, 2) the number of persons using each of the eight colors in the death drawing by type of subject, 3) a separate analysis of the use of the colors in the second drawing, 4) a comparison between the colors used by the DD and the SV subjects, 5) a comparison between the objects of the death and the free choice drawing, and 6) an analysis of the subjects ability to appear relaxed. Any second drawing not related to death (by the subject's description) was accepted as a "relaxed" response. An analysis was also done comparing the use of colors for both sets of drawings for persons participating twice in the interview.

Drawing Description. Of the ninety-four "death" drawings there were twenty-six types of drawings identified. It also included a verbal response which was done in place of a drawing which may or may not have been death related. A list of the twenty-six types of pictures is in Appendix J. This appendix also has a detailed listing of each subject's drawings: if the first drawing was considered a death drawing, the description of the drawing, color(s) used in the first drawing, whether the subject appeared relaxed (in
terms of drawing an unrelated second picture to the topic of death), whether
the first and second drawings were the same or different, and a description
of the second drawing.

The analysis of the drawing descriptions was done for all subjects at
the first administration. Nine subjects drew a person in a coffin or a casket
and an additional nine subjects drew a grave, tombstone, or one place of
burial. Six subjects drew a dead person or persons (without a death object
such as a casket or grave). These pictures frequently required the subject
verbally describing the person as dead. For example, "my grandmother who
died," "my dead aunt," or "John Kennedy." Five subjects drew a sick or dying
person (both were accepted as a death drawing since it is commonly a fear
associated with illness). Four subjects drew a symbolic picture which was
often abstract representing a belief of the subject. These drawings
frequently were described as a "freeing of the soul," "movement toward
something," "explosion of energy," etc. (These symbolic drawings were all
done by the SV subjects). Three people drew living people. No description or
response was obtained to indicate that the drawing was death related. Three
subjects drew an empty coffin or casket. Three subjects drew an object
(miscellaneous) which was not death related. Three subjects drew a symbolic
person representing death (personification).

No relationship between the "level of death category" and
"personification" was observed. It was obvious in two cases, by the subjects' responses, that the subjects knew there was no such person, but chose to
draw the person as a response because it was what came to mind and
apparently had some kind of meaning for them (both of these were SV
subjects with death categories of 3c). Three subjects drew miscellaneous
death related objects (e.g., baby clothes of dead son of a DD subject). Two subjects drew a cemetery or graveyard (more than one grave), two subjects drew an angel or something representing heaven, two subjects drew a cross, empty tomb or a Christian symbol, and two subjects drew a deaf person and did not change or recognize the difference between "deaf" and "dead." All other drawing types were represented by one subject each: flowers, skeleton, heaven and hell, sunrise/sunset, people who are not sick but will die, self portrait, person killed, verbal death description without a drawing of the Ohio State Fair amusement ride accident, old man and a gun, family of origin without dead father, and a funeral home.

Colors Used for Death Drawings. Tests of the differences between the DD and SV use of the colors for the first and second drawings were done. There were significant differences in the use of two colors. Proportionally more SV than DD subjects used green: chi-square = 4.28, df = 1, p<.05, and proportionally more SV than DD subjects also used blue: chi-square = 6.53, df = 1, p<.01 in the first drawing. In the second set of drawings (anything the subject wanted to draw) proportionally more SV than DD subjects used the colors green (chi-square = 6.46, df = 1, p<.01), blue (chi-square = 3.99, df = 1, p<.05), yellow (chi-square = 12.45, df = 1, p<.01), and brown (chi-square = 3.99, df = 1, p<.05). Table 16 summarizes the use of colors for both the first and second drawings by subject type.

An examination of Table 16 shows that black was used most often as a color in the death drawing and was the third most frequent color used in the free choice drawing. The order of most frequent to least frequent color used for the death drawings is as follows: black, blue, brown, green, yellow, red, purple, and orange. For the free choice drawing the order from most to least
### Table 16

Use of Colors for First and Second Drawings

<table>
<thead>
<tr>
<th>Subject Type</th>
<th>Red</th>
<th>Green</th>
<th>Yellow</th>
<th>Blue</th>
<th>Orange</th>
<th>Brown</th>
<th>Black</th>
<th>Purple</th>
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<tr>
<td><strong>Developmentally</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Disabled</td>
<td>9</td>
<td>8</td>
<td>8</td>
<td>11</td>
<td>4</td>
<td>13</td>
<td>19</td>
<td>6</td>
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<td>Death Drawing</td>
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</tr>
<tr>
<td>n=48</td>
<td>(19%)</td>
<td>(17%)</td>
<td>(17%)</td>
<td>(23%)</td>
<td>(8%)</td>
<td>(27%)</td>
<td>(40%)</td>
<td>(13%)</td>
</tr>
<tr>
<td><strong>Staff Volunteers</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Death Drawing</td>
<td>5</td>
<td>8a</td>
<td>7</td>
<td>11b</td>
<td>2</td>
<td>5</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>n=20</td>
<td>(25%)</td>
<td>(40%)</td>
<td>(35%)</td>
<td>(55%)</td>
<td>(10%)</td>
<td>(25%)</td>
<td>(65%)</td>
<td>(10%)</td>
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<td><strong>Total</strong></td>
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<tr>
<td>n=68</td>
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<td>16</td>
<td>15</td>
<td>22</td>
<td>6</td>
<td>18</td>
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<td></td>
</tr>
<tr>
<td>Drawing, n=48</td>
<td>(46%)</td>
<td>(31%)</td>
<td>(17%)</td>
<td>(29%)</td>
<td>(14%)</td>
<td>(23%)</td>
<td>(42%)</td>
<td>(17%)</td>
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<tr>
<td><strong>Staff Volunteers</strong></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Free Choice</td>
<td>8</td>
<td>13b</td>
<td>12b</td>
<td>11a</td>
<td>4</td>
<td>11a</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Drawing, n=20</td>
<td>(40%)</td>
<td>(65%)</td>
<td>(60%)</td>
<td>(55%)</td>
<td>(20%)</td>
<td>(55%)</td>
<td>(35%)</td>
<td>(30%)</td>
</tr>
<tr>
<td><strong>Free Choice</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>30</td>
<td>29</td>
<td>20</td>
<td>25</td>
<td>26</td>
<td>25</td>
<td>27</td>
<td>14</td>
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<tr>
<td>n=68</td>
<td>(44%)</td>
<td>(41%)</td>
<td>(29%)</td>
<td>(37%)</td>
<td>(30%)</td>
<td>(37%)</td>
<td>(40%)</td>
<td>(21%)</td>
</tr>
</tbody>
</table>

*P < .05. (Proportionally more SV subjects used this color for this type of drawing than OD subjects).

*P < .01. (Proportionally more SV subjects used this color for this type of drawing than OD subjects).
was red, green, black, blue and brown (tied), yellow, purple and orange. Orange, in both drawings, was the least often used. Comparing the total number of all colors used by the two types of subjects it is apparent that the SV used more colors in their drawings (for each subject) and that more colors, on the whole, were used in the free choice drawings for both types of subjects.

Relaxation Observed in the Second Drawings. A subject was recorded as being able to relax if he/she drew a fantasy drawing or any drawing described to be something not related to death, or judged to be a representation of something positive about death. If the first drawing was not related to death and the second drawing appeared to be the same as the first (both drawn with same object or person) the subject was recorded as "cannot judge." If the person drew a second picture related to death, which may or may not have been like the subject's first drawing, the person was judged to not have been able to relax from the death topic. Forty-eight (48) subjects (of the 68 total subjects) were able to meet the relaxed criteria. Five (5) subjects drew death pictures for the second drawing and met the criteria for "not relaxed." Fifteen (15) subjects could not be judged either relaxed or not relaxed. One subject in the "not relaxed" and one subject in the "cannot judge" group were SV subjects. All of the remaining SV (18) were considered relaxed. The relaxed number of DD subjects were 30, with 4 judged "not relaxed." Fourteen (14) DD subjects were judged unable to judge (90% of SV subjects appeared relaxed with 62.5% of the DD subjects judged as relaxed). No further statistical tests were done due to the high number not being judged (22%).
Free Choice Drawing Differences From Death Drawings. A frequency count was made of the total subjects who drew the same drawing for both the first and second drawing regardless of whether the first drawing was drawn meeting the criteria for a death drawing or not. One subject (Subject 41) refused to draw or verbally respond to the request to draw pictures for either of the drawings. Of the remaining 67 subjects, 60 drew different pictures and 7 drew the same for the first and second drawing. This frequency count is different from the relaxed frequency count since subjects who drew the same drawing did not always draw a death drawing for the first drawing so were sometimes in the "not judged" category in terms of relaxation.

Use of Colors for Persons Repeating the Interview. Tests were done to analyze whether the use of colors was different for the type of drawings between the first and second interviews. Using chi-square tests, no significant differences were found for either DD or SV subjects.

Similarities between Death and Free Choice Drawings for First and Second Interviews. Subject of the drawings for the death and free choice pictures were analyzed in terms of whether the subject drew two different drawings (i.e., similar or different) for each of the interviews. The results show no change in this variable between interviews. The DD sample had 3 subjects who drew similar drawings for both interviews, and 13 who appropriately drew different drawings for both the first and second interviews. All 10 SV subjects drew different drawings for both interviews.

Relaxation for First and Second Interviews. Subject type (DD and SV) were separately tested comparing whether the samples changed for the "relaxation" variable. The chi-square test indicated no significant difference
between the two interviews. Interestingly, 1 subject changed in each sample group to be judged from "not relaxed" to "relaxed" between interview one and two (i.e., improvement in one subject in each group for the second interview).

**Findings of Individual Components for the Death Concept**

This portion of the chapter is based on an examination of the interview responses in terms of the concepts universality and irreversibility. No statistical tests were done for this examination.

A frequency count was done to assist in examining the relationship between universality and irreversibility. This frequency count was used to assess which concept was most often correct by the DD sample. Figure 2 presents the combination of concepts possible and the observed frequencies of the presence of the concepts meeting each criteria. (Note: See Categorization Manual for explanation of the "qualified" correct response).

An examination of Figure 2 indicates that 36 subjects responded correctly, either with or without qualification, to the universality questions ("Does everyone die?", "Will you die?"). In comparison, 30 subjects responded correctly, with or without qualification, to the irreversibility question, "How do you make dead things come back to life?", correctly.

One of the initial criteria for death Category 3 is the correct response to both of these concepts (universality and irreversibility) at least after qualification (Category 3a). An examination of Table 13 indicates that 19 subjects met the criteria for Category 3. Figure 2 shows that 26 subjects responded correctly to both universality and irreversibility at least after qualification. An examination of the recording sheets for those not meeting the criteria for Category 3 (7 subjects) found that those subjects did not
<table>
<thead>
<tr>
<th>Present Concept</th>
<th>CORRECT</th>
<th>QUALIFIED CORRECT</th>
<th>WRONG</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>U*</td>
<td>I**</td>
<td>U</td>
<td>I</td>
</tr>
<tr>
<td>1.</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>4.</td>
<td>X</td>
<td></td>
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<tr>
<td>5.</td>
<td>X</td>
<td></td>
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<tr>
<td>6.</td>
<td></td>
<td>X</td>
<td>X</td>
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<tr>
<td>7.</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
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<tr>
<td>8.</td>
<td></td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>9.</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Total</td>
<td></td>
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</tr>
</tbody>
</table>

*U=Universality  
**I=Irreversibility

Figure 2. Universality and Irreversibility Concept Combinations in DD Sample.
express any knowledge of what a dead person looks like (2 subjects) or expressed inaccurate and/or confused information related to causes of death (5 subjects). This area required some careful judgment in terms of deciding if the person recognized that death occurred when certain vital biological functions were damaged as opposed to answers implying some belief in "degrees" of death. For example, one subject stated that Reagan lived (compared to John Kennedy) because he was shot (hit by bullet) only once. This answer suggests the subject does not fully understand that cause of death is related to what body parts are hit versus how often.

Summary

This chapter has presented the findings of this study. A description of the samples was presented with tests indicating that the two samples were significantly different on the WAIS subtest scores, in living situation, death experience, and in the use of colors in the drawings. The hypotheses were tested. All tests supported the predicted hypotheses.
CHAPTER V

SUMMARY, DISCUSSION AND RECOMMENDATIONS

This chapter contains a brief summary of the study, a results
discussion, a theoretical discussion, and recommendations for further study.

Summary

This study explored the concepts of death in the developmentally
disabled (DD) adult. The study established that the responses expressed by
developmentally disabled adults in an interview could be reliably categorized
into a developmental model.

The purpose for the study was to examine if previous death concept
questions used with intellectually normal children could be adapted to be
used with DD adults and if the previous developmental model using Piaget's
cognitive developmental stages would also be applicable. It was also felt that
specific knowledge as to how the developmentally disabled think about death
would be the first step in developing programs in helping them deal with
their death experiences.

The sample for the study was drawn from a population of
developmentally disabled adults employed at ARC-Industries North and West,
two of the four sheltered workshops employing developmentally disabled
adults for the Franklin County (Ohio) Board of Mental Retardation and
Developmental Disabilities (FCB MR/DD). The group from which the sample
was selected consisted of all persons born before July, 1951, who were last
assessed to be functioning intellectually within Level I or II, and had
adequate language skills for an interview. Of the 277 persons meeting these
criteria, 48 subjects were selected. These subjects were stratified by North
and West workshops, sex of subject, age range (21-39 years and 40-60 years) and intellectual level IQ and ID. Three persons were in each cell.

An intellectually normal adult population was interviewed for establishing an adult basis of comparison on the instrument. This population was obtained by written request for volunteers of staff working in the North and West workshops for FCB MR/DD. Equal numbers of males and females were represented in the sample, but age, experience, and intellectual level were not controlled. The sample of staff volunteers consisted of 20 subjects equally divided by sex of subject and workshop. The Wechsler Adult Intelligence Scale subtests Vocabulary and Similarities were given to establish that the samples were from separate intellectually functioning populations.

An instrument was developed from questions asked of intellectually normal children cited in previously published developmental studies. One part was added to the instrument which questioned the experiences regarding deaths of animals known to the subjects as a preparation for discussing deaths of people. No previous study had the same sequence of questions. Since no previous study had studied death with developmentally disabled persons and because the instrument organization was new, a pilot study was done. The pilot study established that DD adults could answer the questions. The interview was given to 8 pilot subjects two times. Differences were found in responses by the subjects between the first and second interviews. Consequently, a repeat portion for the main study was designed.

The repeat sample consisted of 16 randomly selected DD subjects from the original subjects: 8 at each workshop. In addition, 10 staff volunteer subjects (SV) were selected from the original 20 with 5 persons at each workshop. The responses between the two samples showed no significant
changes except in reporting death of grandparents (the DD subjects increased significantly in reporting deaths). Both groups of subjects remained the same in the WAIS subtest scores, death categories, and responses to identified questions such as "Do you ever think about death?"

The data from the interview responses were analyzed to test the study hypotheses. The following hypotheses were posed:

1) Responses given by persons who are developmentally disabled can be reliably categorized into death categories.

2) There is a relationship (p<.05) between the previously measured level of intellectual functioning of the subjects and the sophistication of understanding of death as revealed by answers in the structured interview (death categories).

3) There is no relationship between sex of subjects and the death categories.

4) There is no relationship between the workshop attended by the subjects and the death categories.

5) There is no relationship between age of subjects and the death categories.

6) There is a relationship between the measured adaptive behavior of subjects and the death categories.

7) Responses given by persons who are developmentally disabled are different from those given by workshop staff with respect to death categories.

The assumptions underlying the hypotheses were that intelligence would make a difference in the expressed knowledge about death and that sex and age would have no relationship. All of the assumptions were based on previous findings in studies with intellectually normal children (Anthony,
1972; Koocher, 1972; Lonetto, 1980; Maurer, 1966; Nagy, 1948; and Safier, 1964). The workshops were assumed to not make a difference but were controlled to prevent the workshop variable from being an error factor. It was assumed that persons in the study would be able to accurately recall deaths of significant people in their lives.

There were no assumptions for the AAMD Adaptive Behavior Scale (Nihara, et al., 1974) but there was a possibility that acting-out behaviors, withdrawal, or psychological disturbances could be different from persons with less accurate information about death. This was based on Emerson's (1977) clinical observations. Since this was an exploratory study, it was felt that including the measurement of adaptive behavior also gave the study a wider scope of exploration.

The assumption of a possible difference in adaptive behavior was not expected for personal independence and the cognitive triad. However, these domains have been found to correlate with intelligence (Roszkowski and Bean, 1980). Based on the high correlations of these domains to intelligence level and the high correlation of this study's death concepts to intellectual functioning level, it would appear that the ABS\textsubscript{1} and ABS\textsubscript{2} variables in this population may be highly correlated to intellectual functioning. The null hypothesis was rejected in favor of the predicted hypothesis because the ABS\textsubscript{1} and ABS\textsubscript{2} variables represent half of the domains for part one of the ABS. (These domains are also the domains used for the AB level in a psychological evaluation.) Although not significant, Withdrawal was very close to being significantly related to death category. However, this domain may be more closely related to language skills or the ability to do well in an interview (Roszkowski, Spreat, and Waldman, 1983).
The results supported the predicted Hypothesis 1. The finding of inter-rater reliability was substantial. Therefore, the responses given by persons who are developmentally disabled can be reliably categorized into death categories.

The predicted Hypothesis 2 was supported by the data. Previously measured intellectual functioning level for the subjects was found to be significantly related to the death categories obtained from the subjects' interview responses.

Hypothesis 3 was supported by the data. No difference in death category was found to be related to the sex of the subjects.

Hypothesis 4 was supported by the data. No difference in death category was found to be related to the workshop attended by the subjects.

The results supported the predicted Hypothesis 6. ABS₁ (personal independence: Independent Functioning and Domestic Activity) and ABS₂ (cognitive triad: Economic Activity, Language Development, and Numbers and Time) were found to be related to the death category of the subjects.

Hypothesis 7 was supported by the data. Staff Volunteer subjects' death categories were significantly better than Developmentally Disabled subjects' death categories.

Results Discussion

Societies have developed because mankind has the knowledge that we are mortal. Because we know we are mortal beings, we have attempted to develop methods of extending our mortality such as having children and making written records of our history. The current study explored what the DD individual understood about death. The major finding of the study was that the DD individual has some experiential knowledge of death, but does not necessarily understand that he/she is mortal. This is based on the results
that over half of the DD sample answered incorrectly to the universality and/or the irreversibility question.

If the DD individual does not know he/she is mortal, what does he/she know about death? This study found that it is very difficult to make a general statement about what a DD individual knows about death which would apply to any DD individual. This was because each person discussed death in terms which were unique to his/her personal experiences including his/her own perceptions and how persons in his/her environment had explained (or failed to explain) the events to the DD individual. Discussing death did not appear to be emotionally difficult for any of the subjects except for the few who had symptoms of other emotional problems.

Although for the most part, DD individuals cannot be assumed to understand their mortality, there were DD subjects who did acknowledge that they would die. Persons responding at a higher death category level were found also to be persons functioning at a higher level in measured intelligence (Level D) and were also found to be functioning at a higher level in the personal independence and cognitive triad on the AAMD Adaptive Behavior Scale. No experience differences appear to account for these differences. What appears to be a commonality to all these findings is the apparent ability for these individuals to benefit from their experiences whereas lower functioning individuals have not been able to benefit (learn) as much from their experiences.

The findings of the Safier (animism) Test suggest that the concepts of animism are closely related to the concepts of death. The results, although statistically reliable, are cautiously interpreted for several reasons. First, the responses elicited were yes/no responses. This kind of question, in a long series such as the Safier Test, led subjects to perhaps comply by answering,
but the "yes" "no" made it impossible to make a distinction between those who were consciously answering the questions from those who erratically answered with "yes," and "no." The Safer Test was selected to be included in this study because it was the only study cited which looked at both animism and death. However, previous animism studies (such as Werner and Carrison, 1944) would have been a better methodological model since the subjects were also probed to give reasons for their responses. The Safer Test also did not use or fully cover the scope in the types of inanimate objects. Inanimate objects that do not move were not included so that it becomes more difficult to judge whether movement was an attribute which led subjects into responding that the object had living characteristics.

The intellectually normal population findings suggest another consideration pertaining to the Safer Test. The majority of the SV subjects answered "Yes," "Don't know," or "Other" to the question, "Does a tree hurt when hit?" This response suggests that the SV sample may be a particularly sensitive population to feelings. Many subjects expressed knowledge of studies with plants which show responses to trauma which could be loosely associated as "feeling pain." The subjects, when answering with "Yes" or "Don't know" usually explained their responses which suggests an awareness that their response may not "fit" into the "right answer" category.

Having an intellectually normal adult population not only made the limitations of the Safer Test more obvious, but also made the limitations of the request for "drawing death" more apparent. Many of the SV subjects indicated that the request to draw death was difficult since "death" was not something really visible. Those subjects were told that they could interpret the request anyway they chose. As a result, some drew things which symbolically represented death with such drawings as a bursting forth of
energy or a person representing "death". In contrast to the large percentage of SV subjects who indicated that death was difficult to draw, the DD subjects did not question how or why they were asked to draw death.

The request to "draw death," by its very nature, elicited pictures of objects and people as responses. It is, therefore, redundant to state that the majority of all subjects (DD and SV) responded with concrete subject matter. Approximately half of the subjects drew a dead person, a coffin, a grave scene, or a person who was ill and about to die. The conclusion about what is most visually associated with death are people and places (objects) related to burial.

Originally, a choice of colors were given to see if perhaps black would be associated more with death than other colors. The results did show black used most often. However, black was the third most often selected color in the "free choice" drawing. In other words, black may be frequently used no matter what is being drawn.

The SV subjects used a wider range of colors for both drawings. The DD subjects typically used only one color or all the colors. It appeared as if the SV subjects' rationale for the use of colors were taken from the objects they were drawing. In contrast, many DD subjects verbalized prior to drawing, "—— is my favorite color" or "I think I'll use ———." It might be possible that the DD subjects selected the colors more subjectively than did the SV subjects. Some DD subjects very obviously used all colors stating they did not want to leave any color out.

No other analyses or conclusions about the drawings were made.

This study did not measure the complete spectrum of knowledge related to death. "Knowing" about death can occur from many perspectives. A particular experience (related to death) may influence a particular
individual more than other people or experiences. The ability to distinguish what kind of experiences influence "knowledge" and "emotional knowing" to death were not addressed here. The reader is cautioned to not interpret that death is understood only on an intellectual level. Even though the higher functioning intellectual person answered at a higher concept level for this particular study, he/she is not necessarily assumed to be able to deal with death any better (or worse) than a lower intellectually functioning individual.

Theoretical Discussion

This study evolved out of a need to assist developmentally disabled persons in dealing with the realities of death. Kastenbaum (1977) suggested four areas to be remembered in determining how an individual (child) interprets death. These are the person's 1) developmental level, 2) personality, 3) life experiences, and 4) communication and support system. The developmental level, Kastenbaum's (1977) first area, was selected for the current study with the developmentally disabled for two reasons. First, death is an abstract concept. Abstract thinking is frequently not found in persons functioning in the intellectual deficit ranges. To discuss death with developmentally disabled individuals was particularly difficult and frustrating without any knowledge of their conceptual understanding of death. The second reason for exploring developmental death concept levels was that these had been previously studied in intellectually normal children which provided available elements more readily adaptable for study with the developmentally disabled.

The statistical results indicate that intellectual functioning level of the developmentally disabled person explains his/her understanding of death better than his/her age or sex. The findings for intelligence were consistent with the children's studies. However, age findings were expectedly different
due to chronological age mirroring mental age more closely with intellectually normal children than is observed in developmentally delayed persons. The studies which controlled for both chronological and mental age are more consistent with the present study. For example, Anthony (1972) found that mental age correlated better to her death concept levels than chronological age.

The developmental studies which included intellectually normal children between ages 9 to 12 or above, found that a "mature" concept level was generally reached by the age of 12 years. Not surprisingly, the intellectually normal adults (aged 20-40) in this present study, also expressed death concepts at a "mature" level. Neither their age or intellectual level (measured by the WAIS subtests) were related to the death categories since all expressed the top level of conceptualization. In contrast, many of the DD subjects had not reached a "mature" level of conceptualizing death and although adults, their intellectual level did qualitatively affect their expressed death concept level.

It appears that there may be a "ceiling effect," for the qualitative relationship of intellectual level to death conceptualization. Intelligence does have a relationship up to a point, but loses its measureable effect after this stage is reached.

A "ceiling effect" is also suggested regarding the influence of experience. Kane (1975) found that experience made a difference only with younger children (ages 3 to 6 years). Similarly observed (but for possibly different reasons), older experienced subjects in the present study, did not respond differently from the younger, less experienced, subjects. This finding may be related to how experience is measured, but no matter how experience is defined more experience is implied by age without qualification.
What seems of theoretical interest to this study is why the developmentally disabled person is unable to use his/her experiences in order that he/she may better understand death. For this study, as well as previous developmental studies, Piaget's stages were useful in developing a model for the levels of death concepts. However, his theory describing the child's schematizing activity is less useful for explaining what happens when intellectual development is slowed, delayed, or arrested. Werner is a theorist who is known to have a compatible theory to Piaget (c.f. Langer, 1969). Unlike Piaget, however, Werner made a conscious attempt to account for mental change, wherever it occurred, and to avoid the assumption that development had taken place just because the organism had passed through a long period of time. More specifically, Werner was interested in progressive, arrested and regressive development and explored concept development in children, primitive cultures, mentally retarded and pathologic (schizophrenic) adults (Langer, 1970).

Development was conceptualized by Werner (Langer, 1970) to occur on a continuum of fused to differentiated. For example, Werner felt that primitive mental life did not perceptually differentiate the sensory modalities so that a given stimulus would evoke an undifferentiated sensation. An example of this is the child who states, "'The leaf smells green' and 'That lilac smells awfully nice and yellow.'" Primitive thought was also believed by Werner to consist of transductive associations, a term first suggested by William Stern (Werner, 1957). Transductive associations are based on a perceptual and individualized level which lacks insight into general relationships. The individual forms a global association on limited (small and strict) experience and establishes an idea assumed good in all cases. A part
of this association is the inseparability of all the perceived and associated elements of one concrete experience.

Transductive associations could explain what has been observed in many developmentally disabled. The best example was observed in a school age retarded male who had seen his father "pass out" (become unconscious due to a heart attack) and soon after, die. This student apparently associated, as a result, that everyone dies who passes out. Over a year later, he became very upset when a classmate "passed out" during a seizure because this student "knew" his classmate was going to die.

In the context of this study, many of the subjects' responses to "What makes a person die?" included responses which could be a form of transductive association. Many listed a variety of concrete reasons for known relatives or friends to have died. Often the lists only consisted of illnesses. On one particular occasion, an individual only listed concrete examples of accidents and gave no indication of an awareness that people also die from physical illnesses. In addition to listing reasons which were only in their own scope of experience, the subjects frequently responded as if any person who had a particular illness would be expected to die if he/she became ill with that disease. In other words, cancer was not thought about without completion of the association with death. All normal children are thought by Werner to have transductive associations which, through healthy maturation, develop into a more differentiated and less subjective form of thought (c.f. Langer, 1970). This is due to perceptions becoming less fused and more differentiated and is also perhaps due to the lack of stability (in normal children) in transductive thought (similar to Piaget's disequilibrium). Werner suggests that this lack of stability is the motivating force which makes progressive development possible.
However, if perceptual cues continue to not be differentiated (due to neurological, cultural or pathological factors), events may continue to be associated as a whole (transductive association) even though the cause-effect relationship does not continue to occur as previously associated. Because no differences are perceived, the individual has no need for accommodation and normal development does not occur.

Werner (1957) as well as Piaget (1970) are useful in theoretically exploring reasons for many of the DD individuals' negative response to "Do you ever think about death?" Werner (1957) stressed that the primitive thinker is dealing only with the concrete events occurring in his/her present reality. On a day to day basis, unless death is currently a part of their experience, death is not a part of their reality. Similarly, Piaget (1970) found that a child does not recognize the realm of possibilities until he/she is able to take another's point-of-view (become less egocentric) at which point the child can express that he/she thinks about thinking. Piaget found that this ability did not occur until the Formal Operations stage. This indicates that the question may not always be measuring whether the person is defensive and denying death, but is more likely indicating the person's developmental stage. The question may, however, indicate that the person is very defensive about discussing death if he/she is able to think at the Formal Operations stage. This study did not find the normal adults defensive in the way they answered this question. The reason for this finding, however, is easily accounted for because these subjects were aware, prior to volunteering, that they were agreeing to talk about death. As a result, those who were uncomfortable with the topic obviously did not volunteer.

In the context of Werner and Piaget much of what was observed can be theoretically explained. More specifically, the DD individuals on the whole
probably have very little anxiety related to death. However, because some problems were evident prior to developing this study (which was the reason for the study in the first place) an exploration of where the problems begin, who are most vulnerable to these problems, and what can be done about them, is needed.

One of the most vocal DD persons expressing concerns about death was an individual functioning at the intellectual Level I. Her thought patterns were similar to Werner's (1957) descriptions of primitive magical thoughts which include transductive associations. An example of one of her behaviors was her reluctance to say out loud words which she related to death. Some of the words she selectively omitted were, "die," "funeral," and "casket." She expressed fear of her parents dying as well as herself. Although this woman originally would not speak the words, she was the one who always brought up the topic.

Piaget (1970) and Werner (1957) both acknowledged that difficult and novel tasks may result in a person regressing to a more primitive stage of reasoning. It is possible that the previously described woman and other DD individuals, functioning intellectually within Level I may understand death at a level lower than their abilities for easier and less threatening concepts.

From the current study, it was observed that 7 DD subjects were measured to be functioning intellectually at the Level I and who, in fact, did respond in the interview within the Death Category 2. Examination of these specific subjects' responses showed distortions (possibly transductive associations) which could lead to problems. If disequilibrium has led to some need for resolution (a need for accommodation in the present death concept schema), anxiety may occur until accommodation has occurred. The clinical problem is how to correctly identify a person who has this need without
incorrectly assuming there is a need. Secondly, if there are problems, is there a way to therapeutically help them? Thirdly, what, if any, preventative measures are possible to decrease the likelihood of incorrect associations from occurring?

In summary, the DD population studied, for the most part, are psychologically invested in concrete realities and are affected by death only if it is presently experienced. Concrete thinkers can and do have distortions due to possible transductive associations but may be less concerned about the association than a Formal Operations Stage thinker because the concrete thinkers are generally unaware of problems in logic.

A few of the DD persons, however, may be experiencing distress. These persons are probably those who are capable of Formal Operations logic but have not resolved some illogical transductive associations. This may be due to the difficulty of the death concept and/or because of the emotional associations they have with their death experiences.

Recommendations

Further study is needed which explores experience in the area of death concepts and the developmentally disabled. Based on the previous theoretical discussion, it would appear that DD individuals in Death Category 2 and intellectually functioning at Level II would be less likely to increase in death concept category than a person who is functioning intellectually within Level I who also responded in Death Category 2. Different types of experience, including training, therapy, and time only, could be used to see if any of these could assist in promoting changes in death categories.

Therapeutically, it is important that staff, parents, and, in particular, psychologists, have a means of recognizing problems regarding death in this population. Historically, we have ignored the needs of this population
regarding death. It seems that ignoring death as a reality is not healthy. However, now that we know death should not be ignored we also must not pay more attention to death than the DD individual's needs require. It, therefore, seems important that future studies explore ways of measuring anxiety of death in this population to better assess how prevalent anxiety is concerning death and to better screen those who need help in coping with death from those who do not.

Finally, we who work with the DD population must be careful to not transfer our problems related to death on to the DD individuals. They have their own way of understanding death which is very unique to them. We must be careful to assess what each person understands and use his/her cognitive level for explaining or answering questions about death events. We also must be alert to distortions due to their level of thinking. Death, although understood at a lower concrete level, is not ignored by them when actual events occur. We, too, must not ignore his/her reality but be a willing listener open to discussing the event in a way that fits each person.
LIST OF REFERENCES


Lipe-Goodson, P. & Goebel, B. *Perception of Age and Death in Mentally Retarded Adults*. Mental Retardation, 1983, 21, 68-75.


APPENDIX A

MEMO

Date: July 6, 1981
To: Lynn Krause
From: Arlene H. DeSienzo
Re: Attached Proposal Contents

Attached is an outline with the relevant information pertaining to my proposed research study. The outline was made primarily for you because I want your permission to do a pilot study prior to the completion of my proposal. The pilot study is in addition to the major study. Both the pilot and the major study are spelled out in this outline.

As you requested last Thursday, July 3, 1981 when I spoke to you on the phone, I am also including the completed Human Subjects questionnaire. This questionnaire has not been sent yet to that committee because it first has to meet the approval of my advisor and the academic committee.

I have enclosed the instrument I will be testing in the pilot study, the subject consent form, a rough draft of a letter that would go out to the guardians (if it is needed), a rough draft of the first part of my proposal and an annotated bibliography, if you wish to refer to them.

Thank you. I appreciate your consideration in expediting this for me.
MEMO:

July 27, 1981

To: Lynn Krause, Assistant Superintendent

From: Arlene H. DeRienzo

Re: Research proposal with attached description of Franklin County Board of MR/DD requested involvement

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Attached is the proposal which I had reviewed by my academic committee on July 22, 1981. My committee approves of my topic and interview methodology, but has made some changes. These changes are outlined below:

1) Only two workshops, rather than all four, are needed. The two workshops preferred by my committee are North and West.

2) The MR/DD subjects required will be 48 rather than 64. Of the 48 subjects, 16 will be randomly selected to have a second, 1 hour interview. The subjects will be still identified as previously presented to you; i.e., using intake demographic file cards.

3) In addition to the MR/DD subjects, my committee is requiring that I interview 10 staff members from each workshop (North and West with total number of staff=20). Half (10) of these staff subjects will be asked to be interviewed the second time. Volunteers from the staff who agree to being interviewed after working hours and signing a consent form will be selected. A written request for volunteers will be placed in each staff person's mailbox.

4) The case manager for each subject will be asked to complete an AAMD Adaptive Behavior Scale. The completed scale, following the study, will be returned to the case
MEMO
To Lynn Krause, cont. p. 2

managers so that it can be used for programming purposes.

Based on the number of interviews (a total number of 94), the projected time frame to be interviewing will be August 10 through September 18, 1981. The week of August 3 through 7 will be reserved for getting the sample and obtaining the subjects' signed consents.

I will be unavailable July 30 through August 1, but will call you August 3 to clarify anything needed to obtain permission for the study.

I have made a copy of my proposal, the study outline, and this memo for circulating in the Psychology department of the Franklin County Board of MR/DD.
August 6, 1981
Arlene H. DeRienzo
1243 Harrison Ave.
Columbus, OH 43201
Telephone: 294-8139

Dear Director:

The Franklin County Board of MR/DD has agreed to permit me to study death concepts of developmentally disabled adults working as employees in ARC-Industries. The North and West workshops have been the selected shops for the study. This letter is being written to you to give you the necessary details with regards to the study and your shop's employees, personnel, space and time involvement. I have taken liberty to present this in outline form in order to make the letter easier to follow.

Purpose of Study. The purpose of the study is an exploratory investigation of the awareness and concepts of death in the developmentally disabled adult working in the Franklin County workshops. I found that in my work in the program as a psychology-intern, I had many questions in this area, as did some of my clients. No research has yet been reported in this area for the developmentally disabled.

Time.

a) The study is expected to involve your shop between August 10 and September 18, 1981. Your shop will be involved in the study during half of the time with me being present in your workshop interviewing people approximately eight (8) full days and one-hour after staff working hours seven (7) additional days.

b) The rehabilitation staff, specifically the language specialist(s) and the case managers (of the subjects only), will be providing me with information needed. I will coordinate this through the rehabilitation supervisor.

1) Language specialist. The language specialist (or an appropriate substitute) will be asked to examine the name list of all subjects (24 of the first randomly selected sample and approximately 22 of the second, back-up sample). The purpose
Aug. 6, 1981

Letter to workshop director

of the examination is to identify those persons whose expressive language skills are not understandable and would make interviewing difficult and unproductive. It is likely that this process would take around 15 to 30 minutes.

2) The case managers, of all those persons in both samples, will be first asked to identify those persons on the sample lists who are not their own legal guardians. After all permissions and consent forms have been received and the interviewing begun, the case managers of the consenting employees will be given two items to fill out. The first will be a short, four-question questionnaire asking for information about the type of current residence (natural home, group home, institution, etc), and confirmation of deaths in the family (relationship of who died, generally when death occurred, and reason for death). This questionnaire is expected to take no more than 30 minutes to fill out. (It is not my intent to take any more time than this, hopefully it will take much less. If the history is not easily available, I am asking that I be notified and I will make allowances by individual circumstances, if necessary). The second thing given to the case manager to do is to complete a current AAMD Adaptive Behavior Scale (ABS). If a scale was completed within the last six months, and is still descriptive of the employee, that ABS will be considered appropriate for my needs. The amount of time for doing the ABS will depend on the familiarity with the ABS and the employee. Each case manager will be given a one-page sheet of general directions and I will give any other necessary help as needed. The case manager will not be scoring or adding any of the scores in the scale. This will all be done by me. The ABS could take the case manager about one-hour per person. The scored ABS will be returned to you, the program, after the information I need is obtained, so that you can use it for programming purposes.

3) Work instructors. The cooperation of the instructors for the selected employees will be needed for coordinating schedules and obtaining witnessed consent signatures. The instructor, if time allows, will be asked to witness his/her employee's consent form signature and process. This generally will take on the average of about 5 minutes. No employee will be taken away from his/her work on a priority contract or job or during times of previously scheduled services, lunch or break. I will expect the instructors to let me know when taking an employee puts them at a disadvantage, and I will be most willing to cooperate with them in these matters.
Aug. 6, 1981
Letter to workshop director
page 3

4) employees. Employees selected for this study will all be interviewed once with a random selection of eight (8) being selected for a second interview. Each interview will last approximately 45 to 60 minutes. If the employee and his/her instructor agree to an interview time that requires the employee to be taken away from work for which he/she would have been paid, a mutually agreeable amount of money (based on the person's computed hourly wage) will be paid to the employee. If an individual is willing to stay after his/her working time and is trained to ride COTA (assuming there is a bus that the person can take at a later time), he/she may be scheduled to be interviewed during the time immediately after working time (appropriate notifications to his/her home will be made and no interview after work will occur without).

5) staff volunteers. I need volunteers from the staff of both workshops. To obtain volunteers, I will be placing a memo of request in each staff person's office mailbox. Of those who volunteer, five males and five females will be randomly selected from each workshop. Each consenting person selected from the staff will be interviewed with the same questions as the developmentally disabled persons. Interviews will be held immediately following his/her official working hours at the workshop. It is my plan to schedule one staff interview per day and the approximate time of completion be around 4:30 p.m. Half (5 for each workshop) of the selected volunteers will be randomly selected for a second interview occurring the same as the first.

Space and furniture. I will need a private room or space where I will be able to interview one person. I will need two chairs and a table on which the subject and I may write. The background noise level in the interviewing area needs to be low enough for an audio tape recorder to pick up the voices in the interviews. One area, per shop, for all interviews, is preferred throughout the study for control purposes. The times needed will be from 8:00 a.m. to 4:30 p.m. for eight full days and approximately 3:15 to 4:30 p.m. on the seven additional days I will be interviewing only a staff person. I realize this may require some coordination and cooperation of both your personnel and me, but will try to make as little difficulty in this matter as possible (I am aware that staff members working hours differ and will schedule accordingly).
Human rights of subjects.

a) consents. All subjects will be consenting subjects. If a person is not his/her own legal guardian, permission from the guardian will be received in writing. In addition to the legal guardian's permission, each subject will be required to sign, with a witness present, a consent form. The original consent form will be given to Dr. Lynn Krause prior to the beginning of the interviews. A copy of all consents will be kept by me, also. After all of the first interviews are completed a second sampling will be made from the original sample. Of those selected, a second consent form for the subjects will be witnessed, signed and collected as the first. The legal guardian's first permission will state the chances of the second interview, but since the chance of the second is both difficult to explain and could influence the second's results, the second consent form was decided as necessary for the developmentally disabled.

In addition to the consent form agreeing to the interview about death which will be audio tape recorded, each subject will sign a consent form allowing his/her case manager to provide me with answers to the experiential questionnaire and information from the current AAMD Adaptive Behavior Scale. Once again, this will be included on the legal guardian's consent form letter, also.

The staff volunteers will sign a consent form, also, special consent. If it becomes apparent that a subject needs psychological services to deal with death-related problems, he/she will be asked to sign a release of information, so the appropriate workshop personnel and psychology-intern can be notified.

leaving the interview. All subjects, both the developmentally disabled and the staff volunteers, will all be told in the verbal and written instructions, that if, at any time, they would change their mind, for any reason, they may leave the interview without getting into trouble. Any decision of this nature will be kept confidential.

b) coded interviews. All recordings, both written and audio tape, will be filed and reported without names. All subjects will be given a coded number and all code decipherers will be kept confidential and stored separately. After the study is completed all decipherers for the codes will be destroyed.

Specific to ARC-Industries North. Since I am not familiar with your workshop I will need a current list of the instructors and case managers for the sampled employees. If easily available, a map with names of the instructors and their locations within the workshop would be helpful.
Aug. 6, 1981

Letter to workshop director
page 5

Summary: expected time line.
All dates are approximate based on workshop needs.

Thursday, August 6: Directors receive this communication

Monday, August 10: 1) I will call to see if there are any
questions
2) obtain list of case managers and begin
contacting them about legal guardianship questions.
3) place memos for staff volunteers in mailboxes
4) begin sending out permission letters to
appropriate guardians and asking persons to participate—begin to obtain
witnessed consent signatures

Tuesday, August 11: 1) continue obtaining consent form signatures
2) work on general schedule—i.e., finding
out times not to interview each person

Wednesday, Aug. 12: 1) completion of obtaining consents from
employees
2) follow-up on any legal guardian letters
by phone, if necessary
3) take consent forms to Dr. Lynn Krause
at administration

Thursday, Aug. 13—Sept. 18: 1) begin interviewing
2) distribute questionnaires and Adaptive
Behavior Scales to appropriate case
managers.

Monday, August 31: 1) begin setting second set of consent forms
signed
collect all questionnaires and Adaptive
Behavior Scales

Please contact me if you have any questions or changes that you
would suggest to make this run smoothly for your workshop and me.
I appreciate your time involved in my study, and hope that our
time will benefit the employees of ARC-Industries in the future.
Thank you.

Respectfully submitted,

Arlene H. DeRienzo, M.A.
The Ohio State University
Doctoral student, Psychology,
Developmental Disabilities

cc: Dr. Lynn Krause, Dr. Lynn Collins, Dr. Susan Sherwood, and
workshop rehabilitation supervisors
APPENDIX B

1. Letter to parent or home staff
2. Questionnaire
August 1, 1981

Dear Parent or Home Staff:

My name is Arlene DeRienzo. I am a Psychology-Intern for the Franklin County Board of Mental Retardation/Developmental Disabilities currently on a leave of absence working on a doctorial degree in psychology at the Ohio State University. I am currently doing a study which is a part of my training. The study has been approved by the Franklin County Board of Mental Retardation/Developmental Disabilities and The Ohio State University.

I would like to invite to be interviewed about his/her understanding and ideas about death. I have discussed this briefly with him/her and have given him/her this letter to share with you so that you will know what is happening. I would also like to share some information with me about family members and friends who have died so that I can verify the types of experiences each person has been through.

Tomorrow I will begin asking each person who agrees to help me, to sign a simple consent form which states that participation is voluntary, that all names will be kept private, and no information will be reported with names. If, for any reason, a person would change his/her mind, he/she may leave the interview, at any time, without getting into trouble. Each person agreeing to participate will be interviewed for about 45 minutes to one hour. Some people will be interviewed twice with the same questions. All participating persons will be paid by check based on their hourly wage rate.

If agrees to participate, I will be giving to his/her case manager an AAMD Adaptive Behavior Scale to help me measure each person's adaptive behavior functioning level. I will be asking each participant to give permission for me to use that information for my study. Once again I will keep this information private and report no names.

If you have any questions about this study, please feel free to call me at 234-8139. I will be easiest to reach after 5:00 p.m.

Sincerely,

Arlene R. DeRienzo, M.A.
Please answer the following questions by placing an X in front of the statement which best answers the questions concerning. The responses here are used as a verification of experiences. Return to me in the enclosed envelope.

1) Currently lives at or in:
   - home with parent(s)
   - home with a relative: specify
     - brother
     - sister
     - aunt/uncle
     - grandparents
   - foster home
   - A.D.D. group home
   - private group home
   - Institution
   - Goodwill Dormitory
   - Lives independently
   - other: specify

2) There has been a death of a close friend or family member within:
   - last year
   - 1 and 2 years
   - 2 and 5 years
   - other: specify
   - none

Continue on next page.
3) Relationship of person(s) who died:
   _____ none
   _____ mother
   _____ father
   _____ grandmother
   _____ grandfather
   _____ brother
   _____ sister
   _____ aunt
   _____ uncle
   _____ close friend
   _____ other: specify

4) Reason(s) for death (if more than one person, specify person)
   _____ cancer
   _____ heart attack or trouble
   _____ accident
   _____ pneumonia
   _____ "old age"
   _____ diabetes-related problems
   _____ other terminal disease: specify
   _____ stroke
   _____ complications with surgery
   _____ other: specify

Thank you for your help. Return to Arlene DeRienzo in care of ARC-Industries North or West in the enclosed envelope. If you have any questions please call me at 294-8139.
APPENDIX C

1. Pilot Study Results
Pilot Study Results

1. WAIS subtests: $r = .92$
2. Draw Death: percent of agreement = 87.5
3. Do you ever think about death: $r = .58$
4. What is death: percent of agreement = 62.5
5. Talked about an animal death: percent of agreement = 75.0
6. Known a person who died: percent of agreement = 87.5
7. What makes people die: percent of agreement = 75.0
8. What happens to people when they die: percent of agreement = 75.0
9. Safier Test: $r = -.06$
10. Does everyone die: percent of agreement = 75.0
11. Will you die: percent of agreement = 62.5
12. What will happen after you die: percent of agreement = 37.5
APPENDIX D

1. Letter for Staff Volunteers
August 10, 1981
To: ARC-Industries Staff: North and West
From: Arlene H. DeRlenzo
Re: Volunteering for research study on death concepts

I am currently studying death concepts of the developmentally disabled adults working in ARC-Industries. In addition to the developmentally disabled adults in your workshop, I need volunteers from staff who would be interviewed immediately after working hours, on your own time. You would be interviewed in private, with the same questions I will be asking the ARC-Industries employees. All of your answers would be kept confidential and reported in the study without the use of names. If you volunteer, you may or may not be asked to participate depending on how many people volunteer. If you are randomly selected as a person to be interviewed, you will be asked to spend one to two hours of your time in one to two sessions, approximately one hour each. Hopefully we can find a mutually convenient day and time to do the interview.

If you are willing to be interviewed, please read and sign below and return to me by inter-office mail. Send to: ARC-Industries West, Arlene DeRlenzo, or at West, put in my mail box.

By signing below I am agreeing to help Arlene DeRlenzo. It is okay with me to go and talk with her in private for about one hour. I agree to draw what she asks and answer her questions. Some of her questions are about death. It is all right with me if she tape records my answers and keeps my drawings. I understand that my name will be kept a secret, but Arlene can use my answers and drawings for her work. I have been told that if I do not want to answer the questions I can change my mind and leave without getting into trouble and my leaving will be kept confidential.

Signature __________________ Date __________________
APPENDIX E

1. Consent form for study

2. Consent form for obtaining AAMD Adaptive Behavior Scale information
BY SIGNING BELOW I AM AGREEING TO HELP ARLENE DeRIENZO. IT IS OKAY WITH ME TO GO AGAIN WITH HER AND TALK WITH HER IN PRIVATE FOR ABOUT ONE HOUR. I WILL BE ASKED TO DO THE SAME THINGS WITH ARLENE THAT I WAS THE FIRST TIME. I AGREE TO DRAW WHAT SHE ASKS AND ANSWER HER QUESTIONS. SOME OF HER QUESTIONS ARE ABOUT DEATH. IT IS ALL RIGHT WITH ME IF SHE TAPE RECORDS MY ANSWERS AND KEEPS MY DRAWINGS. I UNDERSTAND THAT MY NAME WILL BE KEPT A SECRET, BUT ARLENE CAN USE MY ANSWERS AND DRAWINGS FOR HER WORK. I HAVE BEEN TOLD THAT I CAN CHANGE MY MIND AND GO BACK TO MY WORK AREA AT ANY TIME WITHOUT GETTING INTO TROUBLE.

________________________________________
SIGNED NAME

________________________________________
DATE

________________________________________
WITNESS
IT IS ALL RIGHT WITH ME FOR MY ARC-INDUSTRIES CASE MANAGER TO ANSWER QUESTIONS ABOUT ME FOR ARLENE DARIENZO. THE QUESTIONS ARE ABOUT WHAT KIND OF HOME I LIVE IN, WHO I KNOW THAT HAS DIED, WHEN THEY DIED, AND WHAT THEY DIED FROM. IT IS ALSO OKAY FOR MY CASE MANAGER TO ANSWER QUESTIONS ABOUT WHAT KIND OF THINGS I DO FOR MYSELF AND WHAT KINDS OF BEHAVIORS I DO WHICH MAY CAUSE ME OR OTHER PEOPLE PROBLEMS IN GETTING ALONG WITH ME. I KNOW THAT ALL OF THESE QUESTIONS AND THE ANSWERS GIVEN BY MY CASE MANAGER WILL BE USED ONLY FOR ARLENE'S WORK. SHE HAS TOLD ME THAT SHE WILL NOT USE MY NAME WITH ANY OF THE INFORMATION GIVEN AND I WILL NOT GET INTO ANY TROUBLE FOR ANY OF THE INFORMATION GIVEN. IF I WANT TO KNOW WHAT KIND OF QUESTIONS ARLENE IS GOING TO ASK, SHE WILL SHOW AND READ TO ME THE QUESTIONS. I HAVE BEEN TOLD THAT IF I DO NOT WANT THESE QUESTIONS ANSWERED ABOUT ME I DO NOT HAVE TO GIVE MY PERMISSION AND WILL NOT GET INTO ANY TROUBLE.

SIGNATURE

DATE

WITNESS
APPENDIX F

L. Coding Sheet

2. Interviewing Recording Form--Instrument
Name

Code

Workshop

Race__________________________Sex: M F

Present Living Situation:

HO HP FH AG OG I OO
<table>
<thead>
<tr>
<th>Session began</th>
<th>Session ended</th>
<th>Ended prior to completion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

D.O.B. | Code: | Level | Test |  
Date of last Test | Present Living Situation: NO HP F AG OG I 00 |
Sex: M F Parents: F (A D O) M (A D O)  
Death in family: Last yr. _____ within 2 yrs. _____ within 5 yrs. ____  
other: _____ specify _____  
relationships: M F GM GF B S A U Other: _____ specify _____  
Knows reasons for death: Yes____No____ Other____ Specify_____  
Behavior:  
_____ cooperative  
_____ reserved  
_____ embarrassed  
_____ compliant  
_____ anxious  
_____ emotional  
_____ flat affect  
_____ refusal/denial  
_____ curious  
_____ other:
Draw Death:

Interview:
Do you ever think of death?

What is death?

Tell me everything you know about death.

Have you ever known an animal (pet) that died?

What was it?

When did it happen?

How did you find out about the death?

Have you ever known someone who died?

Who was it?

When did it happen?

How did you find out about the death?

Who told you?
What did that person tell you?

What makes people die?

What happens to people when they die?

How can you tell when someone is dead?

How do you make dead things come back to life?

SAFIER TEST

Does a dog live?  Is a dog living?  Y  N  DK  O
Does a dog hurt when hit?  Y  N  DK  O
Does a dog grow up?  Y  N  DK  O
Does a dog die?  Y  N  DK  O

Does a ball live?  Is a ball living?  Y  N  DK  O
Does a ball hurt when hit?  Y  N  DK  O
Does a ball grow up?  Y  N  DK  O
Does a ball die?  Y  N  DK  O

Does a tree live?  Is a tree living?  Y  N  DK  O
Does a tree hurt when hit?  Y  N  DK  O
Does a tree grow up?  Y  N  DK  O
Does a tree die?  Y  N  DK  O
Does a boy live? Is a boy living?  Y N DK O
Does a boy hurt when hit?          Y N DK O
Does a boy grow up?                Y N DK O
Does a boy die?                    Y N DK O

Does the moon live? Is the moon living?  Y N DK O
Does the moon hurt when hit?        Y N DK O
Does the moon grow up?              Y N DK O
Does the moon die?                  Y N DK O

Does a cloud live? Is a cloud living?  Y N DK O
Does a cloud hurt when hit?         Y N DK O
Does a cloud grow up?               Y N DK O
Does a cloud die?                   Y N DK O

Does everyone die?

Will you die?

What will happen after you die?

Draw anything you would like to draw.
APPENDIX G

1. AAMD Adaptive Behavior Scale administration directions for study
General directions for filling out the AAMD Adaptive Behavior Scale

An Adaptive Behavior Scale (ABS) is meant to reflect what behaviors are important to you, a significant person from the individual's environment. The answers are from your judgement. The better you know someone, the easier it will be to answer the questions, but no matter how well you know someone, the way you view him or her on the ABS is still a useful viewpoint for me.

Please do not place any numbers or scores in the circles, triangles or rectangles. I will do the scoring. All I need is for you to mark the appropriate descriptions concerning each employee that you are filling out the ABS on. If an ABS has already been done on the behaviors of this individual in the last 6 months, you may transfer the answers to the booklet or give me a copy made of the original. Make sure the administration date is on the copy and who the source of information was. If you need to consult persons in the home of the employee or the employee himself/herself about certain behaviors, do so, but mark the questions on which you did that, and who the source of information was.

There are three general kinds of description statements to be answered in the ABS. The hierarchy statements, recognized by the numbers on the right of the statement with the largest number on top, the check-off descriptions for negative-type statements (such as seen in "Table Manners") and the check-off question in which a check is seen as positive (such as in "Washing Hands and Face"). The second portion of the ABS consists of the second-type negative statements with the variation of circling a two (2) if the behavior occurs frequently and a one (1) if the behavior occurs occasionally, rather than the check as in the first part. The first portion of the ABS is made up of all three type of description statements.

This direction sheet will explain to you how to respond to each type of statement in order to complete an ABS on an employee.

First, the hierarchical question-statement, is answered in the following manner: scan all statements and circle the highest numbered statement's number which describes the person's particular behavior in your judgement.

The second type of response is the negative-type statement. Read each statement. If you have noticed that the person displays a particular behavior and it bothers you and/or persons around him/her, check that statement. In the part two section, if that behavior happens often on a regular basis, circle a "2". If it occurs now and then, circle a "1". If a person has had a behavior in the past, but has not displayed the behavior in the last few weeks (approximately 6 to 8 weeks), do not check or circle the statement.

The third kind of description is identified also by a check, but the check is identifying a positive behavior. Read each statement and check the applicable statements.
directions for ABS

I need the ABS completed by Friday, September 18, 1981. If you have any questions or problems, leave a note in my mailbox. I will get back to you as soon as possible. You may place the completed ABS's in my mailbox, also; however, to protect confidentiality, please put the booklets in an envelop.

The finished ABS's will be returned to the program following my study so that they can be used for future programming.

Thank you for your cooperation.

Arlene H. DeRienzo
APPENDIX H

1. Definition of Terms
DEFINITION OF TERMS

1. Mental retardation:

   Refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior manifested during the developmental period.

   *Mild* mental retardation refers to the degree of mental retardation present when intelligence testing scores range more than 2 and up to 3 standard deviations below the norm (52-67 on the Stanford-Binet and 55-69 on the Wechsler Scales).

   *Moderate* mental retardation refers to the degree of mental retardation present when intelligence testing scores range more than 3 and up to 4 standard deviations below the norm (36-51 on the Stanford-Binet and 40 to 54 on the Wechsler Scales) (Grossman, 1977, pp. 147-148).

2. Developmental disability:

   Refers to a disability attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition of an individual which is closely related to mental retardation or to require similar treatment, and which originates in childhood, is likely to continue,
and constitutes a substantial handicap to the individual (Grossman, 1977, p. 132).

3. Adaptive behavior:
   Refers to the effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of his age and cultural group (Grossman, 1977, p. 122).

4. Level I: Same as mild retardation.

5. Level II: Same as moderate retardation.

6. Sheltered workshop:
   Refers to a facility developed to 1) provide the adult developmentally disabled person with work and work training, 2) provide the developmentally disabled adult with supportive services which assist the individual in reaching his/her potential functioning level, and 3) provide the community with skilled methodical labor frequently not available elsewhere. An individual is assigned to one of four workshops in Franklin County based on geographic location of residence in the county. This study used subjects in the North and West workshops.

7. Death concept:
   Refers to a segment of the group of facts, ideas, thoughts, attitudes, and/or beliefs related to the cessation of life including cultural, philosophical or religious beliefs/affiliation.

8. Preoperations:
   Refers to a period of cognitive development theorized by Piaget. During the preoperation stage the child learns to manipulate real
objects symbolically. The individual remains egocentric and is unable to assume the viewpoint of someone other than himself.

9. Concrete Operations:
Refers to a period of cognitive development theorized by Piaget. An individual at this stage uses the representations developed in the preoperation period and is now able to organize and integrate information from his experiences.

10. Formal Operations:
Refers to a period of cognitive development theorized by Piaget. Specifically, it is considered by Piaget to be the most advanced level of cognitive development. An individual at this stage is able to think about thinking, to deal with what is real and what is possible. Scientific thinking or abstract thinking are both within the formal operations stage.

11. Severe language disorder:
Refers to a subject in this study who either was screened from participating in this study or who was interviewed but had problems communicating verbally to the extent that it was difficult to ascertain what was said by the subject. Because categorizing of such subjects' responses was impossible, a category labeled "Distortion" was made for responses reflecting a language or thought disorder (coded a zero).

12. Thought disorder:
Refers to a subject whose responses were illogical and/or conflicting in content similar to a response made by a person who has a thought or communication disorder. (See severe language disorder above).
APPENDIX I

 MANUAL FOR CATEGORY JUDGEMENT RELIABILITY
STUDY ON CATEGORIES OF DEATH CONCEPTUALIZATION

Preface

This manual begins with a very broad review of death conceptualization. First is a summary of the categorization used for this study. This is followed by an outline of previous work of other studies. Thirdly, is a more detailed explanation of the categories for this study. These three parts are the minimal background needed for making category judgments.

This background is followed by the directions for using the decision chart (which follows) and for making the category judgements.

Background Introduction

Death conceptualization, for the purpose of categorizing in this research, follows the Piagetian model of cognitive development. Basically, there are the three areas of pre-operational thought, concrete operations and formal operations.

When these three levels are applied to death concepts we find that level one is exemplified by a person who is ignorant of death, although he/she may express an awareness of being exposed to something related to death. This level
was designated as "Category 1." A distinction was also made between apparent disinterest with no knowledge, and little knowledge with expressed awareness. These were labeled "1a," and "1b," respectively.

Concrete operations helps to understand "Category 2." A person in this category answered the questions with specific and familiar experiences. These kind of responses were found to occur when the person also had not clearly established that death was final and/or that everyone including himself/herself dies. In addition, this person had great difficulty in communicating an understanding of what "death" is or what a dead person looked like (for example, a dead person compared to a sleeping person or a person in a coma was not clearly understood).

The category 3 response is from a person who knows death is final, that everyone dies, and can express at some level how death is recognized. As in formal operations, this person has some form of logical problem-solving and has made some form of generalizations for efficient thinking and problem-solving. The "quality" of these generalizations were expressed in what seemed to be observable and measureable levels so that three sub-levels were assigned: "3a," "3b," and "3c," with 3c including the most current scientific definition and symptoms expressed.
SUMMARY OF AUTHORS' CATEGORIES FOR ANSWERS TO DEATH QUESTIONS

Anthony, 1972

A. Ignorance and inability to respond to the word in the vocabulary list and lack of concern or interest. It is important that the child show a lack of concern as well as ignorance.

B. Show an interest combined with a limited concept which may be erroneous.

C. Does not show or express inability to understand the word or observed fact. Reference is made to humanity only or associated phenomena not logically or biologically essential.

D. Characteristically, there is no apparent inability to understand the word or the event. Reference to humanity only or specifically as in C Category, may be combined with logical or biological essentials or with generalizations.

E. Definition or description refers to logical or biological essentials.

Lonetto, 1980 (stated into categories by this reporter, not Lonetto)

1. Interchangeability of life and death -- living
on under changed circumstances (generally ages 3-5 years). This stage is devoid of causality, younger child is tolerant of ambiguities.

2. a. Death is caused by an external agent, and b. (concurrently) the child has a growing interest in the rites of burial (generally ages 6-8 years).

3. Adultlike standards of death as the end of life, scary or painful, or seen by abstract "great blackness." (Generally, ages 9-12 years).

Koocher, 1972

1. This group includes fantasy reasoning, magical thinking and/or realistic causes of death which are marked by egocentric reasoning as demonstrated in one or more special cases. The symbolism used here is closely tied to the child's experiences and may require extended explanation. EXAMPLES: "You die when God reads your name in his book," or, "... if you go swimming alone."

2. This group includes specific means of inflicting death, with or without intention. Naming specific weapons, poison, or assaultive acts are all included in this group. EXAMPLES: "... guns, bow and arrow, rat poison, and getting beat up."

3. This group includes relatively abstract clusters of more specific possibilities. The child who states or implies that death is a natural process
is in this group. The idea of physical deterioration or naming classes or potential causes also belongs here. Specific causes may be named frequently as illustrations of the broader classes. EXAMPLES: "... old age, illness, a worn out body," or "... accidents, like getting hit by a car or falling off a roof."

Nagy, 1948

1. (Characteristic of 3-5 year olds) deny death as regular and final process. Death is a departure, a further existence in changed circumstances. Death is temporary. There are degrees of death.

2. (Generally ages 5-9) Death is personified, considered a person. Death exists but children try to keep it distant. Only those die who the death-man carries off. Death is an eventuality. Death is outside us and not universal.

3. (Generally ages 9 and above) It is recognized that death is a process which takes place in us, and the death is the perceptible result which is the dissolution of bodily life. Death is inevitable. Death conception is realistic and their general view of the world.

Safier, 1964

Flux: The central idea being that life and death are
temporary. Death is not perceived as the irre- vocable point beyond which life stops. The idea of flux permits an unlimited number of deaths, interspersed with periods of life.

Yes and No: Death is no longer reversible. Death however, is evitable. One can escape death ultimately. Death is personified in this stage. Death may catch someone or fail to catch someone. Any indication of a personified death trying to catch his victims with the possibility for escape for the victim would come under this category.

Adult and Pseudo-Adult: Death is substantially seen within the adult limitations. Death is permanent. Death is inescapable. The concept of death may be misapplied; however, the idea of an irreversible, inescapable death fits into this category.

Undecided: On the basis of the answers the judge does not feel justified in making a decision.

Contaminated: The judge felt that the interviewer led the child to a particular response; that the response was one not arising spontaneously out of thinking of the child.
CATEGORIZATION SUMMARY FOR DD STUDY

Distortion

It is unclear what the person knows based on the interview. This is apparent by answers which are not appropriate to the question or the person, within the interview, disagrees with previous statements he/she said, and the person makes no attempt to qualify or resolve the conflict in logic. The interviewer has generally indicated when language problems may have led her to hear an answer which in context may have been heard incorrectly. Since an attempt was made to screen out a person with language problems, there are not very many. However, there were persons who did have language problems which were discovered only during the interviewing session. If language appears to be the major problem, (rather than ignorance on the concept "death," or the person has an apparent thought disorder recognized by "word salad" and "echolalia"), the category is "distortion." There are often comments to that effect on the recording sheet if this is the case; but, listening to the tape may assist in making a judgement consistent with other judges.

Category 1 (overall)

This category includes all responses which are answered negatively to the questions, "Does everyone die?" and "Will
you die?". **Category la** is the category which indicates overall ignorance and an unconcerned approach to the subject. All the answers given are either "don't know" or answers which appear as though the answer is given to comply with the interviewer's requests. These interviews are often done by persons with very primitive levels of drawings, but not consistently. **Category lb** is the category which indicates that the person has enough awareness about death to get some appropriate information which, on the face value of the answers, appears to be correct. This is often found in the direct experiences of the person, in that the individual has known an animal or a pet that died. The separation between la and lb is the difference between whether the responses indicate curiosity and awareness or not. The curious, and the persons with some semblance of knowing anything, even though marginal and incorrect, are category lb.

**Category 2**

This category includes the responses which indicate a lack of knowledge of either universality or irreversibility. This category often includes a great deal of information about death which may be irrelevant and/or inaccurate. There are often many descriptions about what happens to the body and other burial rites which may be accurate.
Category 3 (overall)

Category 3 is generally an adult or pseudoadult level of conceptualizing death. This category describes responses which almost always expresses an accurate knowledge about both universality and irreversibility. In other words, those who fit into this category have answered "yes" to "Does everyone die?" and "Will you die?" and "You can't" to the irreversibility question (or other acceptable statements).

Category 3a includes those interview responders who recognize that death is final and that everyone will die, including himself/herself, but does not express very much other information and may add very little to his/her answers about "What makes people die?" and "How can you tell when someone is dead?". This category, for these two questions, state more specific examples with very little evidence of making the generalizations required for Categories 3b and 3c.

Category 3b recognizes some basic death symptoms to "How can you tell when someone is dead?", but is not sophisticated enough to state anything to do with such things as the brain stopping or that there are no brain waves.

Category 3c is the category which has good generalization development for the questions, "What makes people die?" and "How can you tell when someone is dead?".
Typical responses would have generalizations with or without specific examples. For example, in response to "What makes people die?", this type of responder would say something like "Illnesses of different kinds and accidents, both of which impair the body to function and maintain life." In response to "How can you tell when someone is dead?", this response category would include something to do with body functions ceasing and especially the essential ones which are easily observable; breathing stops, the heart stops. These subjects may also include such things as the person's face appears different, touching them feels cold, the body turns stiff, and color changes.
CATEGORIZATION DIRECTIONS

Categorization for the purpose of this study is accomplished with a decision-tree or flow chart. The chart begins with concepts which best discriminate the subject's responses and includes all concepts necessary for insuring that the subject's responses do fit criteria for a particular category level.

The decision-tree is accomplished by answering yes or no to a set of questions and/or criteria. Each question is in a numbered box. In the body of the Manual, the judge will find more specific information explaining what is to be included in the decision for that particular numbered question. The information is found by the number (user's manual has been finger tabled for quickly changing sections). Each section repeats the statement from the flow chart under the subheading "Concept." This is followed by a description of "Where to Look" in the interview recording sheet (which is also finger tabled and color coded: green is page 3, yellow is page 4, blue is page 5). Background information is included to inform the judge of the logic behind the decision. This is followed by examples of acceptable/correct responses and unacceptable/wrong responses for that particular category level (the same response may be acceptable at
a lower category level). At the bottom of the first page the judge is told what section to turn to, based on whether the decision question is answered "yes" or "no." This is placed in a box to make it quick to locate and is always on the same page with the finger tab (even if there are several pages of acceptable and unacceptable examples).

A simple category recording form is to be used for summarizing judgement (see following page). It includes a place for the subject's code, the concept areas, and the resulting judged category. This can be filled out by checking the appropriate box as the questions on the decision-chart are answered.

A short explanation of how the interviewer recorded what happened during the interview is included in the manual to assist in assuring that correct judgements are made for the universality and irreversibility concept areas.
Distortion problem
Universality
Irreversibility
Death Symptoms
Cause
Definition
Confusion
Drawing
Clarification of Recording Sheet Reporting Notations:
In order to make notations as quickly as possible and to interfere with the interview as little as possible, abbreviations were used as much as possible. In reading the responses the following will help clarify what occurred:

1) **dk**: Subject stated he/she did not know.

2) **---**: Interviewer reworded the question to get a better idea of the subject's knowledge or meaning. In the area of irreversibility and universality the (---) is particularly important in that the subject initially did not respond correctly and the question was reworded or stated to make sure of the subject's response. If response was originally correct, dashes were used to indicate subject expounded on his/her ideas but only important parts were recorded (most frequently these dashes were shorter).

3) **X---**: On about two interviews, the interviewer assumed a word which was later X'd out because it could not be credited to the subject in light of the quality of the completed interview. The X frequently
occurs toward the first of the interview because of the unfamiliarity of the subject to the interviewer.

4) gf: Grandfather
5) gm: Grandmother
SECTION 1

Concept: Did subject have language or thought disorder?

Where to look: Somewhere on the first page or within the body of the interview, notes were made suggesting that the person's speech was difficult to understand or that answers were difficult to follow. Look on the first page under "Behavior" to see if there is a comment regarding language such as "perseverative," "aphasic," "language problems," "echolalic-like," etc.

Background: First of all, the intelligence scale used for identifying the subjects was either the Stanford-Binet or the Wechsler Adult Intelligence Scale. In order to be assessed at the Level II or above, it is usually expected that the person is at least able to talk. However, to assure that the study would consist of subjects who could speak intelligibly in response to questions, the subject list was given to either the rehabilitation supervisor or the language specialist to screen out persons whose speech was not understandable. However, a few persons were not identified whose expressive language was either unintelligible or suggestive of a thought disorder.

A language problem was recorded generally by writing the words assumed to have been spoken with a question mark and comment concerning whether this was what an individual
Section 1 (continued)
said. Persons whose speech was understandable, but had answers which were very illogical and "off the subject" were suspected as having a thought disorder. If the responses were sometimes accurate, but most frequently included unusual, irrelevant responses, this section is responded to affirmatively.

If this section is answered YES (affirmatively) turn to Section 9
If this section is answered NO (negatively) turn to Section 2

Affirmative judgement to Section 1:

If recording sheet, on first or third page includes statement written by the reporter such as:

1) perseverative
2) aphasic
3) language problem
4) echolalic or echolalic-like
4) thought disorder

AND the response frequently -

1) do not make logical sense
2) are off the subject
3) answers are X'd with comments that could not be understood but the interviewer assumed a word that, analyzed after the interview was complete, was most likely assumed (incorrectly,
Section 1 (continued)

most likely) or "given" to subject by the
interviewer with improper leading questions.

Negative judgement if above criteria is not met.
SECTION 2

**Concept:** Did subject answer universality questions correctly?

**Where to look:** Turn to page 6. This is the last page of the interview recording form and is right before the subject's drawings. At the top of the page is the second half of the "Safier Test". This is followed by the universality questions, "Does everyone die?", and "Will you die?"

**Background:** In order to answer acceptably to the universality questions the subject has to indicate an awareness that death is inevitable and that he/she is aware that death is a part of everyone's life, eventually, including his/her own life. Some subjects misunderstood the question, thinking perhaps, that the interviewer meant now. However, for purposes of judging the interview, if the response was initially wrong, the judgement, FOR THIS SECTION, is unacceptable. (Correct answers, after qualified by the subject or by the interviewer are acceptable at a different category level).

If this section is judged YES (acceptable/correct) turn to Section 3
If this section is judged NO (unacceptable/wrong) turn to Section 16
Section 2 (continued)

ACCEPTABLE/CORRECT RESPONSES (must be correct for both questions):

1) Yes; oh sure
2) Physically, yes
3) No man knows the hour of his death, yes
4) Yes, guess so
5) When they're dead, yes yes
6) Yes, sometime
7) When their time comes; yes when my time comes
8) Not everyone, not the Lord -- yes, some day
9) sure
10) Yes when I get old. Never can tell though
    ... don't have to be old though
11) Sometime, guess so, yes
12) Yes. Can't answer when. Don't know -- up to
    man above
13) For my (interview) purposes yes -- religious
    view appointed once to die -- I got into
    rapture there (last time)

UNACCEPTABLE/WRONG responses:

1) No
2) No, not quite everyone
3) Not me
4) I hope not
Section 2 (continued)

5) dk (don't know) -- some of them do

6) Everybody lives

7) Not everyone -- people young

8) No, no way

9) Shook head no (Who won't die?) Jesus and

   them up in heaven. (We people here on earth
die sometime?) No.

10) Yes/just some of them

11) No -- everyone will but those that are still

   living when Jesus comes back (this is unac-
   ceptable because requires interviewer question)
SECTION 3:

Concept: Did subject answer the irreversibility correctly?

Where to look: Interview question regarding irreversibility is on the fifth page above the "Safier Test". The question is "How do you make dead things come back to life?"

Background: The irreversibility question was worded so that the responder would not be able to answer correctly by merely attempting to comply with the request or try to please the interviewer. If the response was initially incorrect, the response is not considered acceptable for this category level. However, the wrong response, followed by a dash (---) indicates the question was reworded (or the actual words used by the interviewer are placed between parentheses). If this is then answered correctly, it will be dealt with in Section 10.

If this section is judged YES (acceptable/correct) turn to Section 4
If this section is judged NO (unacceptable/wrong) turn to Section 10

ACCEPTABLE/CORRECT responses:

1) You can't; you can't—gone you gone forever
2) Impossible
3) I can't do that, can't do that
4) You don't, or don't
5) I don't think that's possible, I don't think you can
Section 3 (continued)

6) Can't -- plants can, people can't

7) No can't, but Frankenstein he came back to
    life in movies

8) No, ground, and heaven are all I know

9) Not really true-used to believe in evil
    spirits - used to believe in olden days -
    I don't believe - can't

10) No

11) I don't think you ever can, never seen it
    done

12) No way -- up in heaven

13) You can't, go to heaven - Jesus say only one
    that can make people come alive

14) Can't bring back - kind of obvious to do if
    get to the hospital room to emergency room
    can save them -- can die in ambulance

15) Huh uh (can't?) huh uh

16) You can't - can water plants, can't do that
    for people

17) Keep things about Elvis - listen to records -
    can't come back (subject was discussing mem-
    ories as opposed to actual physical life
    therefore an acceptable answer)
Section 3 (continued)

18) If totally dead no way - possibility only to serve purpose of someone higher than me

19) CPR - other than that dk. Seeds are essentially dead and give live symbolic back to life offspring maybe reincarnation (this answer indicated that she was aware that everything is relative and was assumed to be talking metaphysically; the context of the entire interview has to be assessed to ascertain person knows that death is final, as we know it.)

20) No dead for long, adrenaline and CPR, but dead for any length of time doesn't come back to life.

21) Attempt CPR and mouth to mouth resuscitation if fails no coming back then you can't. If time to go you go.

22) You don't - do automatically just shell (body) dies and just takes a new form - believe in reincarnation

23) I don't think something that is dead comes back to life

24) God can - we can't - God does it (renew them) all the time

25) Physically you don't - mentally you can or don't literally, but can through memories
Section 3 (continued)

26) I don't - Jesus does - on earth He could raise
the dead - the people died later (though--this
indicates that person recognizes that everyone
eventually dies and that it is then final)

27) You can't with the body - soul never dies

28) I think you can - people have come back with
a purpose - CPR and stuff. Fact whether dead
medically or not, questionable - was the brain
gone (Subject indicated that if brain gone
then death is final and it depends how death is
defined)

29) No -- all dead things make dead things come back
to life -- bodies decay - die - enrich the soil.
Life creates life

30) Only one person can do - Jesus and can in
the mind - can't in the physical sense

31) Physically don't, unless special medical equip-
ment, but die eventually anyway

32) You don't - do on own [if going to happen]

ACCEPTABLE/WRONG responses:

1) Anything indicating don't know, or not sure
   of answer

2) Question omitted by interviewer
Section 3 (continued)

3) Water tree -- can't water dead people, not sure whether you can make dead people come back to life
4) Say a prayer
5) Raise them up, help them, pick 'em up - come back to life
6) Yes -- no
7) God, from the Lord - at church (subject is unsure)
8) God makes go back to life - go up in heaven, all of grandma in heaven (appears unsure)
9) dk
10) See em-a ghost-seen a ghost of grandfather (abbreviated gf)
11) Nobody - dk - how to do that
12) Yea, ya does
13) dk -- dk -- maybe Lord upstairs
14) Don't know if you can - can believe in God, dk. not sure
15) Can make dead things come back to life but don't know how
16) Everybody know me
17) Can't remember you can make things come back
18) dk -- dk if you can
19) God rose from the dead then he's alive come back to heaven again -- yes you can -- some-
Section 3 (continued)

things to do with the heart

20) Dig em up - stand em up and make them walk

21) dk if you can

22) Hard to explain - a friend who is a Christian -

Jesus said - we could resurrect the dead - we

could if we have the faith.
SECTION 4

Concept: Included heart stop, breath stop in death symptoms.

Where to look: Primarily death symptoms are found in the question, "How can you tell when someone is dead?" This question is on page 4. Another place in the interview with supporting information is the question "What is death?" (page 3). All of page 3 and 4 (up to Safier Test) also need to be skimmed for supporting death symptom knowledge.

Background: Symptoms were divided into essential symptoms (high priority) and "symptoms" observed in dead persons which may not necessarily differentiate life from death. In order to be at the highest level of information, the subject had to include "stop breathing" (or a statement meaning the same thing) and "heart (pulse) stop" (or a statement meaning the same thing such as blood flow stop). A very good inclusive statement such as "No vital functioning" is acceptable and is actually preferred. Other information such as "brain stop" makes the answer even more sophisticated, but is not required because the question may imply visible symptoms to the subject.

If this section is judged YES (acceptable/correct) turn to Section 5
If this section is judged NO (unacceptable/wrong) turn to Section 11
Section 4 (continued)

ACCEPTABLE/CORRECT responses: (Should not include anything erroneous)

1) Breathing and heart (pulse) stop
2) No vital functions; no vital signs
3) Brain stop
4) Don't respond, no body functions registering
5) Stop body functions -- motor response gone
6) Obvious decay - no pulse or breath
7) Sure after undertaker has had him/her -
   check pulse, brain dying - human problem
   could not tell
8) All the machines just humm - brain death
9) They don't come - look funny - don't breathe-
   check pulse - blood pressure still there -
   subject implies right after death

UNACCEPTABLE/WRONG responses:

Any response not including something similar to the above.
SECTION 5

Concept: Included generalization about illness and accidents as causes of death.

Where to look: The primary question examining this concept is on page 4, "What makes people die?" Skim pages 3 and 4 for any other information regarding causes (for example area discussing person he/she knew who has died).

Background: Mentally retarded frequently do not make generalizations, but this interview attempted to differentiate those persons who did from those who did not. A generalization could be a statement as sophisticated as "The degenerative biological process or a severe enough trauma (external or internal) to stop the body functioning," or as simple as "illness or accidents." Acceptable answers must include indication of both illness and accidental kinds of deaths. Some persons indicated murder and killing, suicide. For purposes of this study, two generalizations including illness and a form of trauma (external or internal) is acceptable or one good scientific generalizations such as something degenerative, a trauma, ... breakdown of vital systems." If individual subject had a very complete symptom answer, this section is considered acceptable with a very broad generalization.

If this section is judged YES (acceptable/correct) turn to Section 6
If this section is judged NO (unacceptable/wrong) turn to Section 16
Section 5 (continued)

ACCEPTABLE/CORRECT responses:

1) Sickness, accidents or illness and accidents

2) Disease and accidents - disease when body gets old and wears out and accidents - car wrecks, get hurt

3) Natural causes - mother, cancer; father real bad stroke; accidents, run over by a car (subject makes generalization and then gives a concrete example, this is the most appropriate kind of response)

4) Sickness - shoot themselves, Hari Kari - suicide.

5) Sick and can't get well - give up and die; accidents, pneumonia, cancer

6) Break down of body or unwillingness to live

7) Accidents, old age, nature, God taking somebody off earth and replace with new life

8) Lots of different things, something degenerative, a trauma, severe shock to system, break down of vital systems

9) Two ways - spiritual, physical - suicide combination of two. Physical would be like disease, old age, themselves, other people. Spiritual is giving up on yourself.
Section 5 (continued)

10) Illness, accidents, physical calamity

11) (discussed under "Tell me everything...." on page 3). Comes about from illness or accident.

12) Illness, car accidents, accidents of any kind, violent things

13) You don't die -- continue on -- major body dysfunction

14) Life forces cease - natural process of living

15) Physical dysfunctions (probed: "What brings on physical dysfunctions?") Way live life, predetermined, haven't decided (This answer accepted because in the complete interview, subject indicated a realization of brain death)

16) Number of physiological things or broken heart or stamina to want to stay alive (symptom included brain stop, blood stops flowing)

UNACCEPTABLE/WRONG responses:

1) dk (not followed by some generalization which is acceptable)

2) anything that does not include a generalization as discussed above

3) Number of different things, illness, old age (did not include accidental kinds of death)

4) Sin
SECTION 6

**Concept:** Included idea expressing biological ceasing of life in definition of death.

**Where to look:** Primarily look on page 3 under questions, "What is death?" and "Tell me everything you know about death." More than any other concept, this one will require you to read the entire interview for content. Other areas to be read are, "What makes people die" and "What happens to people when they die?"

**Background:** These interview inquiries were expected to get responses which were factual more than emotional. However, a great many persons (especially staff) gave emotional or philosophical answers rather than factual. If all the answers up to this point (which is following the decision chart on the most sophisticated level) have been acceptable, then this particular concept is judged leniently. Answers which may or may not have scientific support but is acceptable by a religious group or other social belief systems, are to be considered acceptable IF enough information is given in the concept areas, death symptoms and causes for death, which confirms that the individual could state or comprehend an acceptable scientific definition of death such as "death is the biological ceasing of life."

If this section is judged YES (acceptable) turn to Section 7
If this section is judged NO (unacceptable) turn to Section 13
Section 6 (continued)

ACCEPTABLE/CORRECT responses:

1) Biological ceases: someone dies, life goes out
   and only the soul exists -- only body there

2) End of physical life ... brain stops working
   or to cease living

3) End of physical - but continue spiritual -
   soul leaves body - heart stops, breathing
   stops, brain stops

4) Absence of life - all functions stop

5) End of physical body, but not for your
   soul - body just stops

6) Body stops function, stopping of all bodily
   functions, or body quits working

7) Departing from earth - just being out of
   present form into different form - quit
   breathing, heart quits, no more pulse; no
   more life

8) When physical body goes out

9) Freeing ... decomposing ... soul expansion

10) (Under symptoms) stop body functions - motor
    responses just gone

11) When a living thing dies ... it stops main-
    taining itself and decomposes

12) Separation from life
Section 6 (continued)

13) Itzu ... passing and change
14) Passing to a different experience - only body
dies.... higher place of consciousness
15) Transformation point
16) Someone passing - body dying and spirit passing
either to heaven or hell
17) Life is constant process of dying -- death is
process necessary and essential to growth.
Move from this present life situation to a
newer one
18) Removal of soul by body and judged by God in
the end
19) Think final resting
20) End of living - body just stops functioning

UNACCEPTABLE/WRONG responses:

1) When somebody dies (uses derivative of word
to explain word without any more information)
2) When somebody passes away
3) dead just dead
4) When people die
5) When the Lord tell you you have to go, can't
wait
6) When people die; when a person dies; when
someone dies; when somebody dies; when you die
Section 6 (continued)

7) Something that make me cry, hurt my feelings --
    they just pass away

8) Die-go to funeral

9) They fall over... die, then they're gone, have
    funeral service, burial, put you in a grave ...
    gravestones

10) Death is just death, actually they're not dead,
    up there, in heaven with God, I Hope. Bible
    says someday come back to earth for eternity

11) You cannot talk

12) Jesus - nail to cross

13) Can't hear can't do anything, they don't live,
    they get buried, go up to the moon

14) Person dying feel bad about special person ...
    the dead have feels

15) Think of scary pictures (general associations
    with calamities, but unclear and confusing)

16) Saw friend down in ground ... funeral - funeral
    home

17) See somebody die - get upset - makes people
    sad

18) Sky, heaven, die, pass away

19) If somebody dies you can't see them anymore

20) When they bury them - go to the funeral
Section 6 (continued)

21) Dead, when you die - have to go to heaven -
    Lord makes you go

22) Person leaving - never comes back - start by
    getting sick finally die, man upstairs decides
    where you go ... 

23) Discussed accident read in newspaper and hear
    on news (TV). (Symptom section) Don't move,
    don't breathe

24) Person is going to die if not breathing. If
    not breathing know you're dead

25) Somebody dead, when you die

26) People die or get shot

27) Sick, die, have to be buried

28) Two types - physical and spiritual - God takes
    somebody off earth and replaced with new life...
SECTION 7

Concept: Had an appropriate drawing of death.

Where to look: After the interview recording sheets. First picture is labeled #1. If there are three pictures, look at the second one (labeled #1b). This was the second drawing given when subject misunderstood directions (no subject in this study at the highest category level required the second drawing).

Background: All pictures were accepted if subject could verbally support the connection between the picture and death. If person expresses that the person was "alive" or "dead" the picture was not acceptable (unless sick).

If this section is judged Acceptable drawing turn to Section 8
If this section is judged Unacceptable drawing turn to Section 14

ACCEPTABLE/CORRECT pictures:

1) Dead mother (or aunt, person, sister, friend, relative)
2) Graveyard scene
3) Heaven and earth
4) Underground people
5) Person in coffin or casket
6) Person dying
7) Person having a heart attack
8) Flowers - reminds of heaven
Section 7 (cont'd)

9) People who will die
10) Skeleton
11) Woman "skilled" halloween (maybe meant skeleton)
12) Coffin or casket
13) Sick woman
14) Baby clothes of dead son
15) John Kennedy
16) Old man with gun
17) Tombstone
18) Angel - heaven
19) Energy -- breaking away
20) Three crosses
21) Symbolic person -- expressed as symbolic (need inquiry to assure that person is not thinking of death as a person)
22) Funeral home
23) Family with vacant spot for dead father
24) Sunrise, sunset
25) Person and cross
26) Empty tomb
27) Open door
28) Tree where want to be buried
29) Heaven, hell and grave
30) Relatives crying
Section 7 (continued)

UNACCEPTABLE drawings:

1) Deaf person
2) Ship
3) Refused to draw a picture
4) President Reagan
5) Scribbles - no explanation
6) Self - no explanation except alive
7) Hand (drew around own hand)
8) Mother (alive without an explanation)
9) Sun
10) Miscellaneous objects
11) Television
SECTION 8

The category for this subject's responses is 3c.

It is recorded as a 6.
SECTION 9

The subject's responses are confusing and distorted.

Distortion is scored as a zero (0).
SECTION 10

Concept: Did subject answer irreversibility question AFTER qualification?

Where to look: Page 5, last question above Safier Test, "How do you make dead things come back to life?"

Background: Initially the subject did not answer the question correctly. If the subject has stated he/she does not know, the interviewer stated, "Can you make dead things come back to life?" This is a qualification given by the interviewer. If the response is then correct, the answer is considered acceptable with qualification. Usually this entire interplay during the process would be recorded something like the following: "dk---no." The qualification question was indicated by the ---. This is then followed by an appropriate (or inappropriate) answer.

If this section is answered YES (acceptable) turn to Section 11.
If this section is answered NO (unacceptable) turn to Section 23.

ACCEPTABLE/CORRECT responses following probe or qualifications:

1) No
2) You can't
3) No -- die some day
4) God, from the Lord - at church (you can't?) no.
Section 10 (Continued)

5) dk -- I don't think can--just go up to heaven
6) dk--shook head (doesn't think you can)
7) I dk -- (can you?) no
8) Everybody know me (can you do that?) no can't do that
9) dk-dk if you can (can you make dead things come back to life?) no
10) If question was only stated: can you make dead things come back to life (in error of interviewer) and answer was no (must be scored as qualified correct answer)
11) dk-cant
12) Hard to explain - to a friend - Jesus said we could resurrect the dead - we could if we had enough faith (accepted as qualified answer because he supported with religious belief which has support in a society)

UNACCEPTABLE/WRONG responses (still appears as if possible or unsure)

1) Accidentially omitted during interview
2) Not sure whether you can make dead people come back to life
3) Can make things come back to life
Section 10 (continued)

4) Unsure

5) Nobody - dk - how to do that

6) Yeah ya does. don't get that

7) dk---dk -- Maybe Lord upstairs

8) Don't know if you can---can believe in God, dk
   not sure

9) Can make dead things come back to life but
   don't know how

10) Can't remember---you can make things come back

11) God rose from the dead then he's come alive
    come back to heaven again---yes you can---
    somethings to do with heart - heart beats in
    a dead person

12) Dig em up, stand em up and make them walk
    (why not do it?) too hard (interviewer probe
    may have led subject to answer no to "Can
    you make dead things come back to life?) No

13) dk if you can
SECTION 11

Concept: Included at least one accurate death symptom.

Where to look: Primarily death symptoms are found in the question, "How can you tell when someone is dead?"
This question is on page 4. Another place in the interview with supporting information is the question, "What is death?" (page 3). All of page 3 and 4 (up to Safier Test) also need to be skimmed for supporting death symptom knowledge.

Background: Any one symptom observed in a dead person is acceptable in this category if it is a "priority" symptom not confused with sleep or a coma.

If this section is judged YES (acceptable/correct) turn to Section 12.
If this section is judged NO (unacceptable/wrong) turn to Section 19.

ACCEPTABLE/CORRECT responses:

1) Any response acceptable in Section 4
2) Breathing stop
3) Heart stop (pulse)
4) Body cold (icy)
5) Body stiff
6) Doctor pronounces it, feel heart-stopped-pulse

UNACCEPTABLE/WRONG response:

1) dk
Section 11 (continued)

2) Does not include any of the above or acceptable responses listed in Section 4.

3) Eyes closed (only eyes closed without further support)
SECTION 12

**Concept:** Included generalization about either illness or accidents as cause of death?

**Where to look:** Page 4, question "What makes people die?" Make sure to skim pages 3 and 4 for any added information.

**Background:** Being aware of only accidental kinds of death or deaths related to only illness indicates a narrow awareness of cause. A generalization regarding either illness or accidents is required at this level. Because old age is a generalization implying illness it is judged to be acceptable at this category level as a generalization, although this concept alone can lead to confusion if it is thought of as exclusive cause. If old age is the only thing expressed, other support for recognizing that sometimes people die when they are not old was preferable. (This is why it was not acceptable without illness and accidents at a higher level even though Koocher, 1972, accepted it at his highest level). Because widely accepted Biblical training states sin is why all must die, that belief system is considered also as acceptable at this category level if it is logically supported. Some subjects generalized in one area (either illness or accidents), but listed specifics in the other. That is acceptable at this level, but not at the higher category level. If the
Section 12 (continued)

subject gave specific examples along with generalization, this is considered a very acceptable way of communicating an understanding of the cause of death.

If this section is judged YES (acceptable/correct) turn to Section 13.
If this section is answered NO (unacceptable/wrong) turn to Section 19.

ACCEPTABLE/CORRECT responses:

1) Any answer acceptable in Section 5
2) Sickness; from being sick
3) Accidents; accidental
4) Illnesses
5) Natural causes
6) Sick and can't get well
7) Hurt real bad like car accident
8) Die of all different things (lists specific illnesses) don't take care of health
9) Gets sick and die
10) Old age; old age-not taking good care of themselves - cancer, could be anything
11) Diseases, natural causes, old age
12) Heart attack, diseases, poison ivy (can die) almost got in my eye and die...
13) Sin
14) Sick, heart trouble, taking pills
Section 12 (continued)

UNACCEPTABLE/WRONG responses:

1)  dk (not followed up by acceptable answer)

2)  Anything that does not refer to sickness, illness, old age, murders (killing) or accidents or religious answer which is included in an interview which indicates person could understand or express a scientific generalization

3)  When God gets ready for ya (example of an answer given without any support to answer)
SECTION 13

**Concept:** Included accurate information in death definition (may be minimal, but has to be accurate).

**Where to look:** Primarily look on page three under questions, "What is death?" and "Tell me everything you know about death." More than any other concept, this one will require you to read the entire interview for content. Other areas to be read are, "What makes people die," and "What happens to people when they die"?

**Background:** At this particular level, it is not important that the person do a good job defining death. Rather it is important that the person give some indication that he has knowledge about death, but may have difficulty in communicating his/her ideas, consequently did not ever fully define death as in the higher level. Some persons gave emotional rather than factual answers. If a religious group or other social belief systems are known to believe similarly, the response will be considered acceptable. Answers must be considered, however, for content which indicates that the subject is confused. IMPORTANT NOTE: If it appears that the subject is confused because there are errors in his/her thinking, the response is considered unacceptable.

If this section is judged YES (acceptable/correct) turn to Section 14.
If this section is judged No (unacceptable/wrong) turn to Section 21.
Section 13 (continued)

ACCEPTABLE/CORRECT responses

1) Any response given in Section 6 under ACCEPTABLE
2) Pass away
3) Dead - just dead
4) When the Lord tell you you have to go can't wait
5) When people die; when a person dies; when someone dies; when you die; when somebody dies (any one of the above)
6) Something that makes me cry, hurt my feelings. They just pass away
7) Die - go to funeral
8) They fall over...die, then they're gone, have a funeral service, burial, put you in a grave...gravestones
9) Death is just death, actually they're not dead, up there, in heaven with God, I hope. Bible says someday come back to earth for eternity
10) Saw friend down in ground...funeral - funeral home
11) End of living-body just stops functioning
12) See somebody die - get upset - makes people sad
13) Sky, heaven, die, pass away
14) Lose their last breath and pass away ... last time I'll see them
Section 13 (continued)

15) If somebody dies - you can't see them anymore
16) When they bury them - go to the funeral
17) Dead, when you die have to go to heaven -
    Lord makes you go
18) Person leaving - never comes back - start by
    getting sick ... finally die, man upstairs
    decides where you go ...
19) Sick not able to get well - give up hope
    (under what happens) just pass away, bodies
    terminate, rot
20) Don't have any life in ya
21) Discussed accident read in newspaper and hear
    on news (symptom section) Don't move, don't
    breathe.
22) Person is going to die if not breathing. If
    not breathing know you're dead
23) Somebody dead, when you die
24) People die or get shot
25) Sick, die, have to be buried
26) Two types - physical and spiritual - God takes
    somebody off earth and replace with new life ...
    stop body functions - motor response gone

UNACCEPTABLE/WRONG responses:

1) You can not talk
Section 13 (continued)

2) Jesus - nail to cross

3) Can't hear can't do anything, they don't live,
   they get buried, go up to the moon

4) Person dying feel bad about special person.
   The dead have feels

5) Think of scary pictures (general associations
   with calamities, but unclear and confusing)
SECTION 14

**Concept:** Had an appropriate death drawing or verbalized about an appropriate image without drawing.

**Where to look:** After the interview recording sheets. First picture is labeled #1. If there are three pictures, look at the second one (labeled #1b). This was the second drawing given when subject misunderstood directions.

**Background:** All pictures were accepted if subject could verbally support the connection between the picture and death or if the subject matter was obviously related. If person expressed that the person was "alive" or "dead" the picture was not acceptable (unless sick or was explained to have a connection with death). Some subjects refused to draw a picture. If the person refused, but explained or described an appropriate picture, that kind of response is acceptable at this level.

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If this section is judged YES (acceptable/correct) turn to Section 15.
If this section is judged NO (unacceptable/wrong) turn to Section 22.

**ACCEPTABLE/CORRECT drawings:**
1) Any drawing listed under Section 7 as acceptable
2) Described a scene without drawing of a fair-ground ride accident where a person was killed

**UNACCEPTABLE/WRONG drawings:**
1) Any drawing listed under Section 7 as unacceptable.
SECTION 15

The category for this subject's responses is 3b. It is recorded as a 5.
SECTION 16

Concept: Did subject answer correctly to both Universality questions AFTER qualification?

Where to look: Turn to page 5. This is the last page of the interview recording form and is right before the subject's drawings. At the top of the page is the second half of the "Safier Test". This is followed by the universality questions, "Does everyone die?", and "Will you die?"

Background: The individual has initially answered incorrectly to at least one of the universality questions and had to be asked further questions or the subject voluntarily explained his/her answer and changed the response. Some subjects misunderstood that the interviewer meant that "Will you die?" implied now, or that "Does everyone die?" might have implied all at once. For the purposes of judging the category for this study, this is considered a qualified yes and is only acceptable at this level (no higher category level). Both questions still need to be correct to get any credit at this level after qualification.

If this section is judged YES (acceptable/correct) turn to Section 17.
If this section is judged NO (unacceptable/wrong) turn to Section 22.

ACCPETABLE/CORRECT responses (after qualification):

1) Well yes, when I'm old
Section 16 (continued)

2) everyone will but those that are still living when Jesus comes back

3) First said no, then said yes I will die

4) Everybody lives ---someday yes

5) No-yes---someday (no - too young to die now)

6) No everyone -- people young, yes -- old

7) dk---old-not always die when just old

8) I guess not---don't want to guess might die when 90---yes

9) No---someday will die

UNACCEPTABLE/WRONG responses:

1) No

2) going to be 60
SECTION 17

Concept: Did subject answer irreversibility question AFTER qualification?

Where to look: Page 5, last question above Safier Test, "How do you make dead things come back to life?"

Background: Initially the subject has not answered the universality question correctly: therefore, the subject needs only to answer the irreversibility question correctly AFTER qualification (although it is even better if the subject answer the question correctly in the initial answer), because not being able to answer the universality questions without qualifications indicates that the person is not able to think about death at the highest category level. If the subject has stated he/she does not know, the interviewer stated, "Can you make dead things come back to life?". This is a qualification given by the interviewer. If the response is then correct, the answer is considered acceptable with qualification. Usually this entire interplay during the interview was recorded as follows: "dk---no." The qualification was indicated by the dash. This is then followed by an appropriate (or inappropriate) answer.

If this section is judged YES (acceptable/correct) turn to Section 18.
If this section is judged NO (unacceptable/wrong) turn to Section 24.
Section 17 (continued)

ACCEPTABLE/CORRECT response follow probe or qualification:

1) No
2) You can't
3) no -- die some day
4) God, from the Lord - at church (you can't?) no
5) dk--I don't think...just go up to heaven
6) dk---shook head (doesn't think you can)
7) I dk (can you?) no
8) Everybody know me (can you do that?) no can't do that
9) dk--dk if you can (can you make dead things come back to life?) no
10) If question was only stated: Can you make dead things come back to life?(in error of interviewer) and answer was no (must be scored as qualified correct answer)
11) dk--can't
12) Hard to explain - to a friend - Jesus said we could resurrect the dead - we could if we had enough faith

UNACCEPTABLE/WRONG responses: (still appears as if possible or unsure)

1) Accidentally omitted during interview
Section 17 (continued)

2) Not sure whether you can make dead people come back to life
3) Can make things come back to life
4) Unsure
5) Nobody—dk—how to do that
6) Yeah ya does. Don't get that
7) dk—dk—maybe Lord upstairs
8) Don't know if you can—can believe in God, dk not sure
9) Can make dead things come back to life but don't know how
10) Can't remember—-you can make things come back
11) God rose from the dead then he's come alive come back to heaven again—yes you can—-something to do with heart - heart beats in a dead person
12) Dig em up, stand em up and make them walk (why not do it?) too hard (Interviewer probe may have led subject to answer not to "can you make dead things come back to life?) No.
13) dk if you can
SECTION 18

Concept: Included at least one death symptom (not necessarily high priority).

Where to look: Primarily death symptoms are found in the question, "How can you tell when someone is dead?" This question is on page 4. Another place in the interview with supporting information is the question "What is death?" (page 3). All of page 3 and 4 (up to Safier Test) also need to be skimmed for supporting death symptom knowledge.

Background: Symptoms were divided into essential symptoms (labeled high priority) and "symptoms" observed in dead persons which may not necessarily differentiate life from death. At this particular level, any symptom is acceptable if it is presented in movies, on television, or in books as describing a part of death. High priority symptoms are listed in Section 4 and Section 11. Other acceptable symptoms for this level are listed below.

If this section is judged YES (acceptable/correct) turn to Section 19.
If this section is judged NO (unacceptable/wrong) turn to Section 24.

ACCEPTABLE/CORRECT responses:

1) Any acceptable response listed in Sections 4 and 11.

2) Breathing stop, don't breathe
Section 18 (continued)

3) Heart stop
4) No moving
5) Cold
6) Head covered -- don't wake up; sheet over them
7) Not talking
8) Turn blue; blue and cold
9) Doctor tells me (somebody tells me)
10) Read in paper
11) See in casket
12) Go to grave yard -- see tombstone
13) Stiff
14) See hearse come and take them
15) Face is all blue -- doctor says black people turn white
16) See at funeral

UNACCEPTABLE/WRONG responses:

1) When they get real weak
2) dk
3) Dead people don't talk, don't walk, don't write
4) Leave a skeleton in the grave - saw skelton at COSI that talked back
5) Tubes in their nose
SECTION 19

Concept: Names at least one illness or a description of an accidental cause of death.

Where to look: Page 4, question, "What makes people die?" Be sure and skim pages 3 and 4 for other information.

Background: This level consists of listing specific illnesses, accidents, etc. from which people die. This level is NOT to include answers which are unacceptable; therefore if someone gives one wrong answer (even though has some correct answers) he/she will not be considered for this level. In other words, all erroneous thinking (unless supporting such as stating sometimes can die from a particular illness that is not ordinarily terminal) establishes the person to be at the Category 2 level (the level which frequently has misinformation). If the answer reflects an acceptable teaching, such as a person can die from cigarettes or drinking, that will be considered acceptable and not erroneous even though the person does have incomplete information. Some people do die of illnesses not necessarily fatal; therefore, those illnesses will be accepted as a cause. If a person has reached this level and gives a religious training response it is being considered acceptable (even though it may cause emotional conflict).

If this section is judged YES (acceptable/correct) turn to Section 20.
If this section is judged NO (unacceptable/wrong) turn to Section 24.
Section 19 (continued)

ACCEPTABLE/CORRECT RESPONSES:

1) Operation
2) Car wreck
3) Cigarettes
4) Drinking
5) Cancer
6) Heart attack, heart problems
7) Stroke
8) Take too much drugs, pills
9) Pneumonia
10) Old, old age
11) Car accident
12) Cycle accident
13) Choking
14) Sometimes babies die when born
15) Muscular dystrophy
16) Cold weather
17) Poison
18) Hurricane
19) T.B., tuberculosis
20) Poison in kidney
21) Lupas disease
22) Leukemia
23) Emphasema
Section 19 (continued)

24) War -- Vietnam
25) Bus accident
26) Shot
27) Flu
28) Drown
29) High blood pressure
30) Sclerosis of the liver
31) X-ray treatments
32) Stone trouble
33) When God get ready for ya
34) Sugar pretty bad
35) Asthma
36) Hepatitis
37) Appendicitis
38) Hang self
39) Jump off bridge or house

UNACCEPTABLE/WRONG responses:

1) Put makeup on them
2) Too many kids (babies) did not have any other information to back this up
3) Lots of things -- smoking, drinking...when you go to the doctor right away he cures ya (incorrect concerning doctor always can cure)
4) When you get a certain age
Section 19 (continued)

5) Just die
6) Death (personification)
7) Don't remember
8) Old age - only old people die
9) Anything through air -- Doctor tell you what
    you got (this subject had many correct answers,
    but whole answer indicates some erroneous think­
    ing)
SECTION 20

Concept: Included accurate information in the definition (may be very minimal but must be correct).

Where to look: Primarily look on page 3 under questions, "What is death?" and "Tell me everything you know about death." More than any other concept, this one will require you to read the entire interview for content. Other areas to be read are, "What makes people die?" and "What happens to people when they die?"

Background: At this particular level, it is not important that the person do a good job defining death. Rather, it is important that the person give some indication that he has some accurate knowledge about death, but may have difficulty in communicating his/her ideas, consequently did not even fully define death as in the higher levels. Some persons gave emotional rather than factual answers. If responses are socially acceptable the response will be considered acceptable. Answers must be considered for content which indicates that the subject is confused. If it appears that the subject is confused because there are errors in his/her thinking, the response is considered unacceptable.

If this section is judged YES (acceptable/correct) turn to Section 21.
If this section is judged NO (unacceptable/wrong) turn to Section 24.
SECTION 21

**Concept:** Subject expressed confusion.

**Where to look:** Skim entire interview pages 3 to 5.

(See background)

**Background:** This section is included for subjects who initially are not identified as confused and placed within the Category 2 or below level. If subject has answered correctly on the decision-chart down through to cause, but still shows some confusion, then skim the entire interview and decide if the quality of answers are logical and do not indicate erroneous thinking (as opposed to accurate, but minimal). If answers are accurate, but minimal, the subject is not confused or erroneous and the subject category will remain at the Category 3 level (3A). However, if there is some confusion, it needs to be identified and consequently judged at the Category 2 level.

A person who has a simple religious belief such as "you have to go to heaven - Lord makes you go," is not judged as confused but is judged as expressing an acceptable religious belief system. However, if the person talks loosely about scary things happening, this individual is over generalizing a group of scary happenings with death which is confusing. In other words, the person might think when these happen, death always occurs. An
Section 21 (continued)

example was a subject who said the cause of death was associated with getting hurt with a knife, tornadoes and earthquakes, etc.

If the response to this section is YES turn to Section 24.
If the response to this section is NO turn to Section 22.
SECTION 22

The category for this subject's responses is 3A. It is recorded as a 4.
SECTION 23

Concept: Did subject answer correctly to irreversibility question AFTER qualification?

Where to look: Page 5, last question above Safier Test, "How do you make dead things come back to life?"

Background: Initially the subject has not answered the universality question correctly; therefore, the subject needs only to answer the irreversibility question correctly AFTER qualification (although it is even better if the subject answers the question correctly in the initial answer), because not being able to answer the universality questions already indicates that the person is NOT able to think about death at the higher category levels. If the question was qualified or not, but the final answer is correct, this section is judged acceptable.

If this section is judged YES (acceptable/correct) turn to Section 24.
If this section is judged NO (unacceptable/wrong) turn to Section 25.

ACCEPTABLE/CORRECT responses:

See Section 17 for acceptable responses.

UNACCEPTABLE/WRONG responses:

See Section 17 for unacceptable responses.
SECTION 24

The category for this subject's responses is 2. It is recorded as a 3.
SECTION 25

**Concept:** Subject gave some information about death which is minimal and indicates that he/she knows something about death even though somewhat confused.

**Where to look:** Entire interview including drawing.

**Background:** The subject has given some indication during the interview that he/she is aware of death but does not know very much about death and is not acknowledging that death is final or that everyone will die. A subject which indicates some knowledge makes an attempt at answering the questions, where as the curious person who does not know or communicates knowledge is more likely to state he/she does not know or make guesses which are inappropriate. If subject states cliches that are phrases used a lot in our society associated with death, this person is considered to have some knowledge and is therefore acceptable at this level. Drawings which are appropriate are sometimes support for Level 2. If the drawing is inappropriate, look for cliches such as "pass away," etc. Often this level of subject could talk about a specific death event at a very concrete, physical level.

If this section is judged **YES** (acceptable/correct) turn to Section 24.

If this section is judged **NO** (unacceptable/wrong) turn to Section 26.
SECTION 26

Concept: Was subject curious or aware of death?

Where to look: Entire interview.

Background: If the entire interview includes don't know, don't remember, or blanks, the subject did not appear aware of the subject matter, at all. If however, there seems to be some associations which the individual makes or says he/she wants to learn about death (whether accurate or not) then the subject is judged to be curious and somewhat aware of death, but does not know anything about death. The subject may have continuously associated with "deaf" and no differentiation could be established. The separation between these two levels is very subtle and is usually based on some statement such as "Jesus," or "Easter," which may indicate that the subject at least knows he/she has heard the word "death" before in that context.

If this section is judged YES (acts curious) turn to Section 27.
If this section is judged NO (unaware of death) turn to Section 28.
SECTION 27

The category for this subject's responses is 1b. It is recorded as a 2.
SECTION 28

The category for this subject's responses is la. It is recorded as a 1.
APPENDIX J

1. List of drawing descriptions
2. Drawing descriptions by subject
Drawing Description

00—refusal
01—living person or persons
02—dead person or persons
03—deaf person
04—person in coffin or casket
05—sick or dying person
06—coffin or casket
07—one of a kind—misc. objects not related to death; included scribbles
08—flowers
09—skeleton
10—grave or tombstone; one place of burial
11—cemetery or graveyard; more than one place of burial
12—heaven and hell
13—heaven only or heaven-related; angels, etc.
14—cross or empty tomb; miscellaneous Christian symbols
15—sunrise/sunset
16—symbolic-personification
17—symbolic—not a person but death related; often metaphysical
18—relatives crying
19—other miscellaneous death related objects
20—people who will die in near future
21—self portrait
22—person killed
23—verbal "picture" appropriate to death
24—old man with a gun
25—family of origin with and without dead father
26—funeral home
<table>
<thead>
<tr>
<th>Subject</th>
<th>Colors in death drawing</th>
<th>Death Subject?</th>
<th>Drawing Description</th>
<th>Colors in free choice drawing</th>
<th>Relaxed?</th>
<th>Same/Different</th>
<th>Free choice description</th>
</tr>
</thead>
<tbody>
<tr>
<td>17</td>
<td>black</td>
<td>no</td>
<td>person and sun</td>
<td>red</td>
<td>unsure</td>
<td>different</td>
<td>abstract scribble</td>
</tr>
<tr>
<td>18</td>
<td>blue</td>
<td>yes</td>
<td>mother--dead</td>
<td>all 8</td>
<td>yes</td>
<td>different</td>
<td>house</td>
</tr>
<tr>
<td>19</td>
<td>violet</td>
<td>no</td>
<td>person-deaf</td>
<td>violet</td>
<td>yes</td>
<td>different</td>
<td>wrote name</td>
</tr>
<tr>
<td>20</td>
<td>black</td>
<td>yes</td>
<td>dead aunt</td>
<td>green, orange</td>
<td>yes</td>
<td>different</td>
<td>glass of orange juice</td>
</tr>
<tr>
<td>21</td>
<td>blue</td>
<td>no</td>
<td>person--deaf</td>
<td>red</td>
<td>unsure</td>
<td>same</td>
<td>person</td>
</tr>
<tr>
<td>22</td>
<td>black</td>
<td>yes</td>
<td>heaven and earth</td>
<td>red</td>
<td>no</td>
<td>different</td>
<td>buried person</td>
</tr>
<tr>
<td>23</td>
<td>brown</td>
<td>yes</td>
<td>dead person</td>
<td>blue</td>
<td>yes</td>
<td>different</td>
<td>house</td>
</tr>
<tr>
<td>24</td>
<td>green</td>
<td>no</td>
<td>person, misc. objects</td>
<td>red</td>
<td>unsure</td>
<td>same</td>
<td>person, misc. objects</td>
</tr>
<tr>
<td>25</td>
<td>black</td>
<td>yes</td>
<td>person in coffin</td>
<td>green</td>
<td>yes</td>
<td>different</td>
<td>person</td>
</tr>
<tr>
<td>26</td>
<td>yellow</td>
<td>yes</td>
<td>person dying</td>
<td>violet</td>
<td>yes</td>
<td>different</td>
<td>person</td>
</tr>
<tr>
<td>27</td>
<td>black</td>
<td>no</td>
<td>television</td>
<td>black</td>
<td>unsure</td>
<td>different</td>
<td>radio</td>
</tr>
<tr>
<td>28</td>
<td>red</td>
<td>yes</td>
<td>person/heart attack</td>
<td>violet</td>
<td>unsure</td>
<td>same</td>
<td>person</td>
</tr>
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<td>29</td>
<td>blue</td>
<td>yes</td>
<td>sister who died</td>
<td>brown</td>
<td>no</td>
<td>same</td>
<td>relative that died</td>
</tr>
<tr>
<td>30</td>
<td>black</td>
<td>yes</td>
<td>person (in casket)</td>
<td>green</td>
<td>yes</td>
<td>different</td>
<td>uncle milking cow (looks like first drawing, labeled diff.) casket, pallbearers</td>
</tr>
<tr>
<td>31</td>
<td>brown</td>
<td>yes</td>
<td>coffin</td>
<td>brown</td>
<td>no</td>
<td>same</td>
<td>person</td>
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<tr>
<td>32</td>
<td>all colors</td>
<td>yes</td>
<td>flowers-reminds of heaven</td>
<td>red</td>
<td>yes</td>
<td>different</td>
<td>house</td>
</tr>
<tr>
<td>33</td>
<td>black</td>
<td>yes</td>
<td>grave yard scene</td>
<td>black</td>
<td>yes</td>
<td>different</td>
<td>camping</td>
</tr>
<tr>
<td>34</td>
<td>yellow</td>
<td>yes</td>
<td>person in casket</td>
<td>brown, black, green, blue</td>
<td>yes</td>
<td>different</td>
<td>church and cross</td>
</tr>
<tr>
<td>35</td>
<td>red, green, brown, blue</td>
<td>yes</td>
<td>1 person dying</td>
<td>brown, black, green, blue</td>
<td>yes</td>
<td>different</td>
<td>flowers, design.</td>
</tr>
<tr>
<td>36</td>
<td>black, violet</td>
<td>yes</td>
<td>2 person there, flowers all 8</td>
<td>2 person there, flowers all 8</td>
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<td>different</td>
<td>flowers</td>
</tr>
<tr>
<td>37</td>
<td>black, brown, yellow,</td>
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<td>grave scene</td>
<td>green, yellow, violet, black</td>
<td>yes</td>
<td>different</td>
<td>flowers</td>
</tr>
<tr>
<td>38</td>
<td>red</td>
<td>no</td>
<td>ship</td>
<td>red</td>
<td>unsure</td>
<td>different</td>
<td>abstract scribble</td>
</tr>
<tr>
<td>Subject</td>
<td>Colors in death drawing</td>
<td>Death Subject?</td>
<td>Drawing Description</td>
<td>Colors in free choice drawing</td>
<td>Relaxed?</td>
<td>Same/Different</td>
<td>Free choice description</td>
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<td>-------------------------------</td>
<td>---------</td>
<td>---------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>39</td>
<td>brown, black, yellow</td>
<td>yes</td>
<td>sun, birds, flowers bees, underground people</td>
<td>brown, blue, black, green</td>
<td>unsure</td>
<td>different</td>
<td>birds, ghost</td>
</tr>
<tr>
<td>40</td>
<td>blue</td>
<td>yes</td>
<td>people-will die</td>
<td>black</td>
<td>yes</td>
<td>different</td>
<td>bride</td>
</tr>
<tr>
<td>41</td>
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<td>refused</td>
<td>brown</td>
<td>unsure</td>
<td>same</td>
<td>refused</td>
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<tr>
<td>42</td>
<td>black, violet, brown red, orange, green</td>
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<td>self</td>
<td>black, violet, brown, red, green</td>
<td>unsure</td>
<td>same</td>
<td>self</td>
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<tr>
<td>43</td>
<td>blue</td>
<td>yes</td>
<td>relatives-dead</td>
<td>black</td>
<td>no</td>
<td>different</td>
<td>casket and hearst</td>
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<tr>
<td>44</td>
<td>none</td>
<td>no</td>
<td>refused</td>
<td>red</td>
<td>yes</td>
<td>different</td>
<td>nice girl</td>
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<tr>
<td>45</td>
<td>yellow, red</td>
<td>yes</td>
<td>skeleton</td>
<td>yellow</td>
<td>yes</td>
<td>different</td>
<td>flower</td>
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<tr>
<td>46</td>
<td>orange</td>
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<td>woman killed Halloween</td>
<td>orange, yellow</td>
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<td>Halloween</td>
</tr>
<tr>
<td>47</td>
<td>black</td>
<td>yes</td>
<td>dead grandma</td>
<td>green</td>
<td>yes</td>
<td>different</td>
<td>boyfriend</td>
</tr>
<tr>
<td>48</td>
<td>black</td>
<td>yes</td>
<td>coffin</td>
<td>red, black, blue, brown</td>
<td>yes</td>
<td>different</td>
<td>self</td>
</tr>
<tr>
<td>49</td>
<td>blue</td>
<td>yes</td>
<td>person in coffin</td>
<td>red</td>
<td>yes</td>
<td>different</td>
<td>big fat man</td>
</tr>
<tr>
<td>50</td>
<td>all 8</td>
<td>yes</td>
<td>grave yard</td>
<td>red, green, blue, black, brown</td>
<td>yes</td>
<td>different</td>
<td>airplane</td>
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<tr>
<td>51</td>
<td>brown</td>
<td>yes</td>
<td>person in coffin</td>
<td>brown</td>
<td>yes</td>
<td>different</td>
<td>living people</td>
</tr>
<tr>
<td>52</td>
<td>brown</td>
<td>yes</td>
<td>sick woman</td>
<td>brown</td>
<td>yes</td>
<td>different</td>
<td>house</td>
</tr>
<tr>
<td>53</td>
<td>black, brown</td>
<td>yes</td>
<td>open grave</td>
<td>black, orange, blue, red</td>
<td>yes</td>
<td>different</td>
<td>self</td>
</tr>
<tr>
<td>54</td>
<td>black</td>
<td>yes</td>
<td>grave of father</td>
<td>yellow, red, brown, black, green</td>
<td>yes</td>
<td>different</td>
<td>house, tree, sun</td>
</tr>
<tr>
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<td>black</td>
<td>yes</td>
<td>baby clothes of dead son</td>
<td>yellow, blue, black, green</td>
<td>yes</td>
<td>different</td>
<td>house</td>
</tr>
<tr>
<td>56</td>
<td>red</td>
<td>yes</td>
<td>person in coffin</td>
<td>black, blue</td>
<td>no</td>
<td>different</td>
<td>Jesus and guard</td>
</tr>
<tr>
<td>57</td>
<td>red</td>
<td>no</td>
<td>person</td>
<td>blue</td>
<td>yes</td>
<td>different</td>
<td>house and people</td>
</tr>
<tr>
<td>58</td>
<td>blue</td>
<td>yes</td>
<td>sick lady</td>
<td>brown</td>
<td>yes</td>
<td>different</td>
<td>dog</td>
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<tr>
<td>59</td>
<td>none</td>
<td>yes</td>
<td>no picture, described fair accident</td>
<td>red</td>
<td>yes</td>
<td>different</td>
<td>house</td>
</tr>
<tr>
<td>Subject</td>
<td>Colors in death drawing</td>
<td>Drawing Description</td>
<td>Colors in free choice drawing</td>
<td>Relaxed?</td>
<td>Same/Different</td>
<td>Free Choice Description</td>
<td></td>
</tr>
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<td>------------------------</td>
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</tr>
<tr>
<td>60</td>
<td>green, brown</td>
<td>yes</td>
<td>blue</td>
<td>yes</td>
<td>different</td>
<td>top (toy)</td>
<td></td>
</tr>
<tr>
<td>61</td>
<td>black</td>
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<td>yes</td>
<td>different</td>
<td>abstract</td>
<td></td>
</tr>
<tr>
<td>63</td>
<td>black, green</td>
<td>no</td>
<td>red</td>
<td>unsure</td>
<td>different</td>
<td>woman</td>
<td></td>
</tr>
<tr>
<td>64</td>
<td>black</td>
<td>yes</td>
<td>yellow, blue, violet</td>
<td>yes</td>
<td>different</td>
<td>Lone Ranger</td>
<td></td>
</tr>
<tr>
<td>66</td>
<td>brown</td>
<td>yes</td>
<td>yellow</td>
<td>no</td>
<td>different</td>
<td>aunt and grandad-dead</td>
<td></td>
</tr>
<tr>
<td>67</td>
<td>violet</td>
<td>no</td>
<td>violet</td>
<td>unsure</td>
<td>same</td>
<td>scribbles</td>
<td></td>
</tr>
<tr>
<td>68</td>
<td>violet</td>
<td>no</td>
<td>blue</td>
<td>unsure</td>
<td>same</td>
<td>self</td>
<td></td>
</tr>
<tr>
<td>70</td>
<td>green</td>
<td>yes</td>
<td>coffin</td>
<td>red</td>
<td>different</td>
<td>self</td>
<td></td>
</tr>
<tr>
<td>71</td>
<td>brown</td>
<td>yes</td>
<td>grave</td>
<td>red, black</td>
<td>different</td>
<td>house</td>
<td></td>
</tr>
<tr>
<td>72</td>
<td>black, brown, green, red</td>
<td>no</td>
<td>self</td>
<td>black, brown, green</td>
<td>unsure</td>
<td>same</td>
<td>self</td>
</tr>
<tr>
<td>73</td>
<td>violet</td>
<td>yes</td>
<td>John Kennedy</td>
<td>red</td>
<td>different</td>
<td>Richard Simmons</td>
<td></td>
</tr>
<tr>
<td>76</td>
<td>red</td>
<td>no</td>
<td>living people</td>
<td>yellow, green, orange, brown, red, violet, blue, black</td>
<td>unsure</td>
<td>different</td>
<td>rainstorm</td>
</tr>
<tr>
<td>77</td>
<td>black</td>
<td>yes</td>
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