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DEVELOPMENTAL DISABILITY AND GRIEF: ASSESSING THE IMPACT OF LIFE EVENTS

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B.A. (University of Waterloo) 1991, B.S.W. Hons. (York University) 1995

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ABSTRACT

The one-dimensional approach of assessing cognitive factors is commonplace in studies investigating people with developmental disabilities. The published literature on grief and people with developmental disabilities was found to be similar in this regard. This study differs by investigating the influence of external social factors on the grief of people with developmental disabilities. A qualitative methodology of semi-structured interviewing was used to collect descriptive information from people with developmental disabilities about their social experiences and experiences with death. Importantly, this methodology allowed the participants to speak for themselves.

The effects of the participants' socialization histories and associated circumstantial losses were found to support specific personality and self-concept characteristics and to also influence the quality of the participants' grief work. The participants' socialization histories of infantilization and didactic communication eclipsed their personal authority to question their circumstances. Such a socialization history was found to yield unprocessed losses which supported defended and vulnerable personalities and self-concepts.

The state of the participants' personalities and self-concepts served to illustrate the result of the general absence of processing accorded to and by the participants of their social and life experiences. Given their conditioned unfamiliarity with questioning their circumstances, their grief was found to include only reactive grief without evidence of existential grieving; that is, an internal questioning about death. This study indicates that just as the participants' social contexts defined how involved they were in determining their lives, their grief was also defined by what their social contexts will bear.

AUTHOR'S NOTE

The term "developmental disability" is used in this thesis. It is used as a generic term referring to "disabilities attributable to mental retardation, cerebral palsy, epilepsy, autism and certain other conditions closely related to retardation in terms of intellectual and adaptive problems and the types of services needed" (Horejsi, 1979, pp.15-16).

The term "developmental disability" is not used to replace the term "mental retardation," but rather to acknowledge a diversity of developmental impairments. To be able to refer to people who are different from the general population in this thesis, a classification needs to be used. The term "developmental disability" is used not because it sounds less offensive, but because it includes a broad group of neurological conditions.

Authors cited in this thesis are not unanimous in their terminology when referring to people with intellectual and adaptive impairments. The various terms used include: mental retardation, mental handicap, developmental delay and developmental disability. The reason for this multiplicity is not that each author is referring to distinctly different neurological conditions, but that each has chosen to use a particular term on the basis of its connotation and his or her audience and personal belief system.

This thesis accepts the inconsistent use of terminology to reflect personal choice rather than as a means to differentiate between types of developmental impairments. Therefore, reference in this thesis to people with "mental retardation" does not exclude people with "developmental disabilities" and vice versa.

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Above all, thank you to the "teachers" who shared their life experiences. To Jim, who was not a participant, but who inspired this research.

Thank you to Marty Laurence, Dean Jannah Mather and Luke Fusco for their support. Marty's consultation and challenges turned my scribbled notes into a research study.

I wish to extend my appreciation to the service providers who invited me into their agencies, gave me a chance to present my ideas, and supported my research. All direct-care staff and those who acted as support persons are greatly deserving of my thanks. And, family members who, in sharing the life events of their adult child or sibling with a developmental disability, also shared their own past. I am grateful for your help.

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You have had to wait a bit, but here it is David, Thank You. Your loving support and sterling ability to bring cups of tea at the sound of my little bell are duly noted.

To each member of RUSH, your work has always spoken directly to me and has supplied me with renewed energy and direction.

And, to my cat, Old Son. Thanks for your company when the hours got long in front of the computer. I am willing to overlook that you still confuse the turning on of my computer with an invitation to swat at the defenseless mouse who lives in the monitor. I would be remiss if I did not thank you for all the times you fell asleep with your head resting against some vital keys on the keyboard.

Areas which seem unclear are by courtesy of Old Son.

"Research must be placed in its proper perspective; those whom we study must be the beneficiaries of the knowledge we gain....I remain opposed to those efforts which insist on identifying mental retardation as a separate sub-area, the understanding of which will be provided by approaches and constructs narrower than or different from those which we employ when dealing with children (read:people) of normal intellect."

Zigler, 1975

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CHAPTER ONE

Introduction

This thesis explores grief and developmental disability from a position that is not represented in the published literature. Most of the literature on this subject fails to recognize the influence of social factors on grief. The published literature primarily assesses either the cognitive understanding of death or the grief reactions of people with developmental disabilities. Both of these positions emphasize cognitive abilities and do not address external factors which may affect grief.

This study asserts that people with developmental disabilities are influenced by the society of which they are a part. The "thoughts, feelings and actions" by which they experience grief are "intertwined with the beliefs, motives and behaviours" (Fisher, 1982, p.6) of the society in which they live. In this study, the life events and social experiences of people with developmental disabilities which impact their self-concepts and personality development and, ultimately, the state from which they approach grief, are considered. By giving such consideration, I am drawing on personal beliefs that people with developmental disabilities are more than their intelligence quotients; that their social experiences are influenced by the condition of having a developmental disability; that they are aware of their differential treatment by society; and that such differential treatment affects the development of self-concept, personality and a personal loss history.

1.1: Rationale for the Study

Historically, researchers have studied the cognitive aspects of developmental disabilities ignoring relevant social and personality factors (Zigler & Burack, 1989). As recognized by Zigler and Burack (1989) and Reiss and Benson (1984), the effect of such a one-dimensional approach is that the mental health needs of people with developmental disabilities have been neglected. It is only in recent years that the mental health needs of people with developmental disabilities have been recognized (Borthwick-Duffy, 1994).

Zigler and Burack (1989) suggest that the emotional difficulties and mental health disorders of people with developmental disabilities were, until recent times, interpreted to be related to the condition of cognitive disability. Such a prejudiced assumption has caused people with developmental disabilities to be pronounced to be acting in certain, usually socially inappropriate ways, because they are "mentally retarded."

The subject of grief and people with developmental disabilities has received little attention (Harper & Wadsworth, 1993; Chambers & Martin, 1993; Kloeppel & Hollins, 1989). Only in the last fifteen years, researchers began to query, and to accept, that people with developmental disabilities understand death and do grieve (Harper & Wadsworth, 1993; Bihm & Elliott, 1982; Carder, 1987; Sternlicht, 1980; Lipe-Goodson & Goebel, 1983). Further, research has revealed that they experience similar grief reactions to the general population (Wadsworth & Harper, 1991). The available research, although scant, establishes that the reactions of people with developmental disabilities to a death are not behaviours associated with cognitive disability, but rather reactions of grief — reactions which are expected of and accepted from the general population.

A premise of this study is that being vulnerable to society's yardstick of intellectual and social functioning generates a unique, personal loss history for people with developmental disabilities. As discussed in the literature review section, the social experiences commonly experienced by people with developmental disabilities develop mainly from North America's social intolerance for people who do not meet "cultural demands regarding intellectual and social behaviour" (Isett, Roszkowski, Spreat & Reiter, 1982).

Social experiences that smack of loss likely impact the personality development and self-concept of people with developmental disabilities. As Kauffman (1994) suggests, the grief process of people with developmental disabilities can be complicated by the "vulnerabilities caused by chronic injuries to the mentally retarded person's sense of self-worth" (p.265). Therefore, as with the general population, the personal loss history of people with developmental disabilities may affect grieving (Lendrum & Syme, 1992) and they may approach the universal concern of grief with a disadvantage (Oswin, 1991).

What this proposed "disadvantage" is, is not specifically defined within the literature. However, Dickerson (1981), Oswin (1991) and Kauffman (1994) suggest that by being maligned, pitied or protected, people with developmental disabilities cultivate poor self-perceptions and face their personal concerns from a deficient personal position. As these authors do not define "disadvantage" beyond inferring a psychologically vulnerable state, this study similalry defines "disadvantage."

1.2: Purpose of the Study

The purpose of this study is to:

- explore the social experiences of people with developmental disabilities;
- explore if these social experiences make people with developmental disabilities prone to particular circumstantial losses;
- explore if these experiences of circumstantial loss throughout the lifetime of people with developmental disabilities affect personality development and self-concept, and create a personal loss history which affects how they approach their grief in the event of the death of a significant other.

1.3: Importance of the Study

It is important for counselors working with people with developmental disabilities to recognize that while below average intelligence is a central defining attribute of developmental disability — thus explaining the literature's focus on cognitive functioning — it should not be distorted to mean a lack of feelings (Huston, 1992). Counselors do an injustice to people with developmental disabilities if they operate from a framework that considers cognitive adequacy to the extent that the effects of socialization experiences on mental health are overridden (Zigler & Burack, 1989).

When supporting people with developmental disabilities to work through grief and loss, it is especially important to understand that they are "not unfortunate human beings, but humans in unfortunate circumstances" (Huston, 1992, p.11). Counselors who neglect non-cognitive factors, such as social and personality factors, will fail to view people with developmental disabilities as whole people.

1.4: Research Question

This study proposes the following research question:

Does the social experience of being developmentally disabled create a personal history of circumstantial loss which affects personality development and self-concept and, ultimately, a disadvantaged state from which to approach the universal concern of grief?

Three sub-questions are generated from this research question. Each will be explored within the literature review section.

1. What are the social experiences of people with developmental disabilities?
2. What are the effects of the social experiences of being developmentally disabled on personality development and self-concept? Do the social experiences of people with developmental disabilities render personalities and self-evaluations which are disadvantaged and "riddled with losses" as proposed by Kauffman (1994)?
3. How do people with developmental disabilities conceptualize death and how do they express and experience grief ?

The inception of this research question is derived from my professional and personal relationships with young adults with developmental disabilities who have struggled with situations of loss. Usually, in trying to unburden themselves and cope with confused emotions, their behaviours are dismissed as expressions of "retardedness." Disregard occurs because "their" communication is sometimes not similar to the usual way people would communicate in like situations.

I have seen people with developmental disabilities treated as if there were a qualitative difference in the situations which affect them, burden them and upset them. I first realized that people with developmental disabilities can experience loss during socialization when a young adult with a developmental disability insisted that he was an orphan. My attempts to explain the word orphan to him and talk of how his parents were present in his life were futile. Rather than try to understand his perception of himself within his family, I was speaking of his "real life" situation. He, however, was speaking from a gut feeling; emotionally, he felt like an orphan.

1.5: National and Provincial Prevalence Rates of Developmental Disability

The prevalence rates cited are based on a review of the literature by the Working Group on the Epidemiology of Mental Retardation (Health and Welfare Canada, 1988). The operational definition of "mental retardation" used by most prevalence studies reviewed by this group is the performance on standardized IQ tests.

The national prevalence of developmental disability is suggested to be at least eight per thousand population for all levels of "retardation." This prevalence rate represents equal rates (four per thousand) for "mild mental retardation" (IQ = 50 to 70) and "severe mental retardation" (IQ < 50).

An Ontario prevalence rate for all levels of "mental retardation" by chronological age per one thousand population is estimated by Lundy (1983, as cited in Health and Welfare Canada, 1988). Lundy's total population sample was 8,265,105 and the method of ascertainment was projected from American census and Ontario caseloads. The operational definition was IQ < 70. Lundy's results indicate that the highest ascertainment occurs between the ages of ten and twenty years, at about seven per thousand. For children under five years, a prevalence rate of 2.3 is reported. Prevalence rates are reported to increase with age until about forty years, when there is a decrease to about four per thousand.

Studies which investigated prevalence rates by sex have consistently reported higher rates for males.

1.6: Conceptual Definitions

The following terms constitute the key descriptors for this study.

1. **Developmental Disability:** A generic term defined as "severe, chronic disabilities of a person which a) are attributed to mental and/or physical impairment; b) are manifested before the age of twenty-two and are likely to continue indefinitely; c) result in limitations in the areas of self-care, language learning, mobility, capacity for independent living and economic sufficiency; and d) reflect a person's need for special care and treatment which are lifelong or of extended duration" (Davidson & Dosser,1982, p.115). Levels of intellectual impairment are not assigned by this definition.
2. **Mental Retardation:** The definition used by most researchers is the performance on standardized IQ tests (Health and Welfare Canada, 1988). Mental retardation is defined as an intelligent quotient of less than 70, with

onset before eighteen years (APA, 1980). An IQ of 70 or below represents approximately two standard deviations below the mean on a standard intelligence test. Levels of intellectual impairment are specified as:

Mild Mental Retardation: IQ level 50 -55 to approximately 70
Moderate Mental Retardation: IQ level 35-40 to 50-55
Severe Mental Retardation: IQ level 20-25 to 35-40
Profound Mental Retardation: IQ level below 20 or 25

3. **Social Experiences:** This term refers to the atypical social experiences associated with developmental disability. This study acknowledges that people with developmental disabilities are not homogeneous. However, the commonality of social experiences of people with developmental disabilities is referred to in the literature by Gabriel (1993), Reiss and Benson (1984), Ingalls (1978), and Wilson (1970). The impact of social experiences on people with developmental disabilities is referred to in the literature as the "social psychology of mental retardation."

4. **Personality:** This term refers to a set of enduring responses or dispositions that determine behaviour (Fisher, 1982).

5. **Self-Concept:** This term is used interchangeably within the literature with the terms self-appraisal, self-identity, self-evaluation, self-perspective, and self-esteem. Self-Concept will be used to mean a personal assessment of one's functioning and abilities, typically in relation to others. As Jahoda,

Markova and Cattermole (1988) note, self-concept is largely determined by the ways in which one is treated by significant others.

6. **Circumstantial Loss:** Losses which are experienced as part of the life-cycle, but which do not happen to all people (Lendrum & Syme, 1992). Circumstantial losses are not "necessary losses" (also referred to as "developmental losses"); that is, their occurrence is not essential for maturation and separation as are universal losses such as birth, weaning and death (Lendrum & Syme, 1992). Rather, circumstantial losses are unique, personal loss events such as divorce, emigration, miscarriage, disability and less tangible losses such as the loss of acceptance, membership, dreams or faith.
7. **Disadvantaged State:** This term refers to an affected ego state, possibly characterized by emotional or psychological deficits, that evolves from exposure to recognizable stressors. It potentially manifests as a fragile ego state; that is, a devalued sense of self (Applegate & Barol, 1989) characterized by a sense of personal inadequacy and of being faulty (Kauffman, 1994).
8. **Grief and/or Grieving:** These terms will refer to a person's internal and external responses (cognitive, affective, behavioural and physiological) to a loss due to a death. While participants in this study must have experienced the death of a significant other, their overt or covert grief was not a selection factor (Emerson, 1977). It was acknowledged that grief reactions do manifest in relation to circumstantial losses.

CHAPTER TWO

Literature Review

As mentioned in chapter one, the literature review addresses the three sub-questions generated from this study's research question. First, Ontario's social policy toward people with developmental disabilities is reviewed in order to chronicle their societal status. Second, the common social experiences of people with developmental disabilities are reviewed. Third, theories of personality development and the self-concept of people with developmental disabilities are reviewed. Reviewed last is the understanding of death and the grief reactions of people with developmental disabilities.

As a preface, two points need to be addressed: heterogeneity and an awareness of self and others. Each point has been inferred by various authors (Ingalls, 1978; Maloney & Ward, 1979; Zigler, 1975).

2.1: Heterogeneity

Discussions about people with developmental disabilities tend to result in generalizations about their experiences and character traits. However, people with developmental disabilities are not homogeneous (Langness & Levine, 1986).

As with each person in the general population, people with developmental disabilities are influenced by "everything from organic factors such as genetic predisposition or cerebral dysfunction to experiences in early childhood to the way (one is) treated by society" (Ingalls, 1978, p.264). That people with developmental disabilities are, like the general population, individually definable by non-cognitive variables such as social experiences and life histories, is acknowledged by the majority of the cited authors.

2.2: Awareness

That people with developmental disabilities are aware of and sensitive to the negative implication of being labeled cognitively disabled and are aware of the discrepancy between society's ideal and themselves is affirmed in the literature (Payne & Patton, 1981; Reiss & Benson, 1984, 1989; Zetlin & Turner, 1984; Goffman, 1963, cited in Edgerton, 1984; Jahoda et al., 1988; Szivos & Griffiths, 1990).

People with "mild" to "borderline mental retardation" are said to have the ability to compare oneself to others (Maloney & Ward, 1979; Reiss & Benson, 1984; Szivos & Griffiths, 1990). As noted by Baroff (1991), the ability to compare oneself with others and to assess being different does not develop before the age of three.

2.3: Ontario's Social Policy and Social History of People with Developmental Disabilities

Maloney and Ward (1979) state that the concept of "mental retardation" indicates that a person has difficulty functioning within a society because of his or her intelligence level. This conception of "mental retardation" involves both the individual and the social system. Both components, the person and the society, need to be understood as "mental retardation cannot be conceptualized as an abstract category transcending social systems...it is tied to a specific status and role in a specific social system" (Mercer, 1973, p.30).

Simmons (1982) provides a comprehensive analysis of Ontario's social policy and social history of people with developmental disabilities. His chronological analysis shows that within the span of time that Ontario has been involved in the welfare of people with developmental disabilities — at least a century and a half — "mental retardation policy" has swayed between four main objectives: (1) to provide asylum; (2) to provide social control; (3) to educate, or (4) to serve social welfare functions for people with developmental disabilities who require government support to live within the community.

Chronologically, intolerance is reflected in Ontario's social history with respect to people with developmental disabilities.

- In the late 19th century, with Ontario's shift from an agricultural to industrial society, there was a custodial movement. People who were seen as a threat to society were committed to asylums and deemed "feeble-minded."
- The "myth of the menace of the feeble-minded" persisted from 1900 to the late 1920s. This myth claimed that "feeble-mindedness" was inherited and that such people represented a disproportionate number within the social problem groups such as criminals, delinquents, the poor, the unemployed and prostitutes.
- In 1914, special education classes were introduced for children with developmental disabilities. Under the guise of education, programs assessed if poor school performance was environmental, suggesting the child was educable after removal of environmental stressors or if the source of difficulties were cognitive, making the child uneducable and best raised in an asylum.

- The 1930s saw the debate in Ontario over the sterilization of people with developmental disabilities.
- In the 1950s, parents' groups established themselves to influence social policies for people with developmental disabilities. Simmons notes that Ontario's parents' movement was similar to the parents' movement in the United States in the 1930s, wherein parents were made to feel embarrassed, ashamed and guilty for their political efforts.
- In the 1960s, Ontarians still conceived of people with developmental disabilities as having chronic, incurable conditions that required institutionalization.
- In the 1960s, social policy on developmental disability received overdue attention, due to U.S. President John F. Kennedy's personal, family-based concern. This U.S. interest influenced Ontario and by 1964 there was federal-provincial interest in deinstitutionalization policies – moving from an institutional-custodial care model to a community-based care model. Programs of deinstitutionalization were initiated in the 1970s to the 1980s.

Simmons (1982) concludes that there has not been a permanent qualitative change in the "relative" position of people with developmental disabilities in relation to other "dependent" groups in Ontario. He cites one shift in 120 years of government involvement: From the 1840s to the 1960s, people with developmental disabilities were "ignored, institutionalized or stigmatized" (p.257); then, in the late 1970s to the 1980s, they were deinstitutionalized or, more to the point, "integrated into the general social welfare population...at the bottom of the social and economic ladder, submerged in the large underclass..." (p.257).

Simmons' finding that negative societal attitudes towards people with developmental disabilities could prevail decade after decade is echoed within other North American-based literature (Wilson, 1970; Payne & Patton, 1981; Isett et al., 1982; Antonak & Harth, 1994).

The prevailing attitudes toward people with developmental disabilities include:

1. A person with a developmental disability is low on intelligence and social independence (Wilson, 1970) and is generally viewed as remaining childlike, dependent and unable to make decisions (Payne & Patton, 1981).

2. North American social tolerability for the types of behaviour associated with people with developmental disabilities which reflect skill deficiency or social maladaptation is invariant. Violence to self, other or property, incontinence and sexual improprieties are ranked as the most intolerable; the lack of basic academic skills being the least intolerable (Isett et al., 1982).

Negative attitudes may support expectations that restrict independence and integration (Antonak & Harth, 1994) and invite experiences of mortification, degradation, rejection and humiliation (Wilson, 1970) in the home, work place, community or residential setting. Common attitudes toward people with disabilities include: "depersonalization, dehumanization, objectification, devaluation, distancing, asexualization, disenfranchisement, imposed helplessness and emphasized vulnerabilities" (Sobsey, 1994a, p.173).

3. Society's unfavourable attitudes towards people with developmental disabilities, relative to other "disabled" people, "can only add to the retardate's problems" (Wilson, 1970, p.231).

2.4: Common Social Experiences

The term "common social experiences" does not imply that there are certain social experiences which are universal to people with developmental disabilities. Instead, it suggests that people with developmental disabilities can have social experiences which are different from the social experiences of the general population (Zigler, 1975; Ingalls, 1978; Payne & Patton, 1981; Edgerton, 1984; Reiss & Benson, 1984). These differences in social experiences can be stated as "common" to people with developmental disabilities or as "atypical" for the general population.

Some authors refer to the common social experiences of people with developmental disabilities as the "social psychology of mental retardation" (Wilson, 1970; Ingalls, 1978). This term refers to how an individual is influenced by and in turn influences the actions of others in his or her social environment. The essence of this term captures, again, the interaction of the individual and society which is at the core of the term developmental disabilities, as previously referred to at the beginning of this chapter.

To consider people with developmental disabilities as a part of, not in isolation from, their social milieu is rare. Ghaziuddin (1988) addresses this issue when referring to the reality that psychological or behavioural symptoms of people with developmental disabilities are viewed apart from their total-life situations.

The social experiences of people with developmental disabilities can also have secondary meaning. Each has the potential to represent a loss. The type of loss referred to is circumstantial loss (Lendrum & Syme, 1992): losses which are unique, personal and which are not necessarily experienced by all people.

While circumstantial losses can include developmental losses such as weaning or death, also included are losses which are less apparent. For example, feelings of rejection and abandonment when separated from family and the family home, residential staffing changes (Kauffman, 1994), the loss of acceptance within the non-developmentally disabled community or personal desires which are made unattainable due to the label and status of developmental disability.

Typically, people with developmental disabilities measure personal evaluation, competence and achievement relative to the lifestyles and life events of non-developmentally disabled people (Payne & Patton, 1981). The outcome of such comparison can be the personal realization of, and struggle with, the discrepancy between an ideal self and the self labeled by society. As they receive the message from society that they are not like others, some develop personalities and self-concepts which are vulnerable, injured and "riddled with loss" (Kauffman, 1994, p.265).

2.4.1: Social Experience of Social Isolation and Rejection

Social isolation and rejection, usually accompanied by ridicule, is reported to span from childhood through to adulthood (Wilson, 1970; Ingalls, 1978; Bogdan & Taylor, 1982; Reiss & Benson, 1984; Langness & Levine, 1986; MARC, 1995). Ingalls, in speaking about how children isolate peers with developmental disabilities, notes that rejection of children with developmental disabilities is not a result of the "retardation" label but rather associated with their socially inappropriate behaviour.

The suggestion that children with developmental disabilities are social isolates, rejected and ridiculed because of their socially inappropriate or immature behaviour, reveals an underlying issue concerning the socialization of people with developmental disabilities.

Edgerton (1984) speaks of socialization for incompetence, meaning that certain expectations and practices typify the socialization experience of children with developmental disabilities. Typically, the parents of children with developmental disabilities restrict them from experiences and responsibilities that would be commonplace for their non-developmentally disabled peers. Parents may restrict and limit exposure to experiences because they perceive them to be too difficult or dangerous; they may directly intervene and do a task "for" instead of "with" their child; and, for adolescents and young adults, restrictions can be placed on sexuality, drinking, smoking and choice of residence (Edgerton, 1984; Levy-Shiff, Kedem & Sevillia; 1990).

Being socialized for incompetence results in dependency and reduced social competence. Because they may have inept social skills due to restricted socialization experiences, children with developmental disabilities often develop socially inappropriate strategies such as bullying, cheating, misbehaving or lying in an attempt to gain acceptance (Wilson, 1970; Ingalls, 1978; Edgerton, 1984; Applegate & Barol, 1989).

Whether the isolated, rejected child with a developmental disability resorts to aggressive behaviour or withdraws out of a sense of worthlessness, their strategies to gain attention more often than not lead to further rejection and restriction (Ingalls, 1978). To relate experiences of rejection to the experience of loss, it can be said that rejecting experiences can foster anxiety about safety and separation as well as cause a person to be protective and defensive about personal feelings (MARC, 1995).

2.4.2: Social Experience of Labeling and Stigma

North American society has certain intellectual and social expectations. Those who do not meet the arbitrary measures of normalcy are referred to by various labels of cognitive deficiency, all of which imply a deficiency in their humanity (Bogdan & Taylor, 1982) and accentuate how people with developmental disabilities are different from the general population (Zigler, 1975; Isett et al., 1982; Maloney & Ward, 1979; MARC, 1995).

As Bogdan and Taylor (1982) assert, labeling confuses the issue of the victim and the villain. People with developmental disabilities who experience abuses of society and failings of social service systems are often blamed for developing maladaptive, socially inappropriate behaviour.

In labeling a person with the condition of developmental disability, society is judging him or her on attributes that it holds to be undesirable and discreditable. To be labeled in such a way, is, as Goffman (1963, cited in Ingalls, 1978) theorized, to have a stigma which devalues one's whole personhood and creates a perception, by self and others, that one is less worthy relative to non-developmentally disabled people.

Jahoda et al. (1990), in reference to Goffman's work on stigma, discuss how developmental disability can be experienced as a loss of a "virtual" self. They assert that Goffman's definition of stigma also denotes the discrepancy between how one actually is and how one is expected to be. Similarly, Szivos and Griffiths (1990) acknowledge that people labeled as developmentally disabled are affected by the loss of a "normal" identity and coming to terms with "handicap" as loss may take years to accomplish.

As Stanovich and Stanovich (1979) and Reiss and Benson (1984) caution, the awareness of the stigmatization of incompetence can have negative psychological implications. Many people with developmental disabilities have an awareness of their stigma of incompetence and, because of their awareness, employ a strategy of denying to others and seemingly to themselves that they have a developmental disability (Edgerton, 1967; Payne & Patton, 1981; Zetlin & Turner, 1984; Jahoda et al., 1988; Szivos & Griffiths, 1990).

Edgerton is credited with referring to the efforts of people with developmental disabilities to deny their condition to themselves and to others and to attempt to pass as "normal" by assuming roles, behaviours and expressions of non-developmentally disabled people as the "cloak of competence" (Payne & Patton, 1981). People with developmental disabilities, as Edgerton (1967) has described, have "less cultural clothing" (p.v) to hide their differentness. Those who don a cloak of competence would appear to be not only aware of their differentness but to also feel threatened by the encounter with rejection, isolation and ridicule if their inabilities are noticed.

2.4.3: Social Experience of Frustration and Failure

People with developmental disabilities can experience frustration and failure from repeated, unsuccessful efforts to succeed at a task that comes easily to peers (Ingalls, 1978) or from the lack of opportunity to advance in life (MARC, 1995). It is not so much a matter of society deliberately raising the bar of social competence that people with developmental disabilities must struggle with but rather the knowledge that, even though they apply themselves, they cannot accomplish certain, basic intellectual or social tasks.

Ingalls (1978) suggests that the personal effect of living with repeated failure and frustration is that it is stressful; can produce anxiety reactions and defense mechanisms; can create lowered opinions of the self and one's abilities; can create an expectancy to fail which likely feeds into an avoidance of trying new tasks; and can develop into a lack of confidence that one can effect change in one's life.

2.4.4: Social Experience of Infantilization

In discussing the expectations and images the label "mental retardation" evokes in the general population, Payne and Patton (1981) suggest that many find the term "mentally retarded adult" contradictory because of the strong view that people with developmental disabilities are forever childlike; that is, dependent and in need of protection and assistance.

Experiencing infantilization in the form of overprotection, not being asked one's opinion and having personal decisions made by others is noted by Reiss and Benson (1984) as having negative psychological implications. Either for those people with developmental disabilities who have experienced life-long infantilization or for those who were abruptly pushed towards independence, confusion about self and others' expectations can be experienced as well as problems with anger and dependency. In addition, the lack of opportunities to experience the typical, maturational "growth experiences" has been identified as a high risk factor for emotional problems (MARC, 1995).

In discussing dependency and the death of a significant other, Kloeppel and Hollins (1989) comment that the condition of having limited ability to understand events coupled with dependency can make people with developmental disabilities "vulnerable to the uncertainties and insecurities normally associated with the death of a loved one" (p.34). As Oswin (1991) suggests, the overwhelming sense of dependency and vulnerability can lead to a person with a developmental disability needing permission to grieve.

Given the heightened dependency of some people with developmental disabilities on others for residential, financial, medical, physical and psychosocial needs (McLoughlin, 1986; Oswin, 1991; Chambers & Martin, 1993; Kauffman, 1994), the death of a caretaker can cause great disruption in daily living. Feelings of abandonment and rejection entangled with dependency and ambivalence can result in a mixture of emotions with a good potential for complicating the grieving process (Kauffman, 1994).

2.4.5: Social Experience of Social Deprivation/Segregation

Generally, people with developmental disabilities do not experience the typical markers of maturation relative to their non-developmentally disabled peers (Langness & Levine, 1986; MARC, 1995). Infantilization is one reason why some people with developmental disabilities do not experience predictable psychosocial milestones. When life-cycle changes do occur, these periods can be experienced as emotionally upsetting and stressful (MARC, 1995).

Social deprivation and social segregation from the non-developmentally disabled community usually occurs at one of three life stages (Richardson & Ritchie, 1989). There can be the transition to an out-home placement: in childhood; in early adulthood when children are generally expected to leave home; or when a home-based caretaker dies. Kauffman (1994) suggests that when segregation to residential living occurs during childhood, adolescence or young adulthood, the broken relationship between the person with a developmental disability and his or her family is often the "hub of loss experience" (p.262) for many people with developmental disabilities.

For those who are not institutionalized and reside in the family home, social deprivation or segregation can be experienced in terms of attending exclusionary, "special" programs or by having overprotective parents who restrict community involvement (Reiss & Benson, 1984).

Social deprivation can affect one's development of an understanding of death. As Ray (1978) suggests, parental protectiveness and restrictiveness in the home environment limits the amount of contact children with developmental disabilities have to usual street games or fairy tales in which the theme of death is central.

Reiss and Benson (1984) report that social segregation can have a negative impact on social development, self-concept and mood.

2.4.6: Social Experience of Social Disruption

Social disruption — the loss of significant others from daily living, the disruption of friendships, the loss of routines and residential changes (Reiss & Benson, 1984) — is closely tied to the issue of social segregation. Even those who have experienced institutional or residential living for a significant part of their lives can experience loss and social disruption because of staff turnover or when residents are re-grouped (Reiss & Benson, 1984).

2.4.7: Social Experience of Cultural Deprivation and Restricted Opportunities

Anthropological studies confirm a link between developmental disability and cultural disadvantage, specifically the conditions of poverty and being a member of a cultural minority (Ingalls, 1978; Edgerton, 1984; Langness & Levine, 1989). The terms "psycho-social disadvantage" or "socio-cultural retardation" (Edgerton, 1984, p.49) refer to people with developmental disabilities related to economical, educational and social disadvantages. People with developmental disabilities who experience cultural deprivation, as noted by Ingalls (1978), are more likely to experience overt rejection and child abuse.

Starting out from a culturally deprived station in life is unlikely to help a person with a developmental disability to avoid experiencing restricted opportunities later in life. As Reiss and Benson (1984) suggest, in terms of the circularity of cultural deprivation and developmental disability, restricted opportunities, such as locating meaningful employment, contribute to feelings of distress, dependency and poverty.

2.4.8: Social Experience of Parental Acceptance

There is almost an over-reporting in the literature of the "crisis" of the birth of a child with a developmental disability. Areas heavily documented are the bereavement response of parents to the birth of a child with a developmental disability; caretakers' perspectives and caretaking dilemmas; and family development.

Less mentioned within the literature is how the initial and ongoing ambivalence of some parents and the family towards the birth and development of the child with a developmental disability is absorbed by the child. For those parents who cannot shift from feelings of guilt, grief, sorrow and/or rejection to acceptance, or even those who remain ambivalent, how is the child affected by the parents' adjustment difficulties?

Applegate and Barol (1989) write that for the parent of a baby with a developmental disability, the baby most likely appears disconnected, has blunted responsiveness and is slow to interact. These conditions are said to disrupt the parent-infant bond (McLoughlin, 1986). Applegate and Barol (1989) report that such a negative identification with the child will compromise both a parent's capacity for optimal parenting and the development of a "supportive holding environment" (p.200).

Applegate and Barol (1989) suggest that a parent's lack of "responsive holding, handling and stimulation" (p.201) can be interpreted by the child as a primary sense of pain and anger rather than a sense of well-being. Another result of low parental responsiveness and/or ambivalence is for the child to initiate his or her own soothing. For the child with a developmentally disability, attempts at self-soothing, attaining external control and attention may take the form of autistic, self-injurious or aggressive behaviours.

Appelgate and Barol (1989) suggest that parents who fail to accept the disability as one aspect of their child's personhood and nurture as they would a non-developmentally disabled child, in effect, leave the child psychologically alone, dropped or abandoned; flooded with anxiety; and incubating a fragmented sense of self.

2.4.9: Additional Social Experiences

Physical and sexual abuse of people with developmental disabilities occurs in larger numbers than in the general population (Reiss & Benson, 1984; Gabriel, 1993). Research from the University of Alberta (Sobsey, 1994b) suggests that 45% of offenders are from outside the family, typically staff from support services. People with developmental disabilities are said to be four times more likely than the "non-disabled" to be sexually abused (MARC, 1995), with more than seventy percent of females with "disabilities" being reported to be sexually abused (Sobsey, 1994b). Victimization raises not only issues of loss, but fear of being preyed on by others, anger and indignation (Reiss & Benson, 1984) and, for some, Post Traumatic Stress Disorder (Gabriel, 1993).

The condition of low social support is associated with people with developmental disabilities (Reiss & Benson, 1989). Low social support being defined as low levels of social reinforcement, high levels of stress, reduced access to individuals who could help problem-solve and offer objective counsel and restricted opportunities for intimate relationships (Reiss & Benson, 1989). In addition, Reiss and Benson (1989) report that low levels of social support are associated with depression in adults with developmental disabilities.

2.5: Personality Development

Personality development research within the field of developmental disabilities has recently started to receive attention (Health and Welfare Canada, 1988). This interest has developed from the field of dual diagnosis, which refers to the condition of developmental disability and mental health concerns (Zigler & Burack, 1989; Gitta & Goldberg, 1994).

As hypotheses about the mental health needs of people with developmental disabilities have been formed and variables which can influence their mental health concerns have been explored, the association between personality development and psychopathology has been the main consideration (Zigler, 1975; Health and Welfare Canada, 1988; MARC, 1995). It is reported that people with developmental disabilities experience the same range of mental health problems as the general population (Zigler & Burack, 1989; MARC, 1995).

Research by Zigler (1975) has sought to classify personality development as a separate entity from intellectual functioning in people with developmental disabilities. Zigler (1975), with various colleagues, has, for thirty years, investigated personality development — the enduring responses or dispositions which are ingrained in a person's character — in people with developmental disabilities.

Besides Zigler's developmental position of personality development, three other theoretical models explain personality development and the dynamics of developmental disabilities: Rotter's social learning theory; Piaget's developmental theory; and Freud's psychoanalytic theory (Rosen, Clark & Kivitz, 1977).

As Zigler's model is sensitive to the life events and social experiences of people with developmental disabilities, his work supports and explains personality development within this study. The other three theoretical models are noted in Appendix E.

2.5.1: Motivational-Cognitive Position

Zigler's thinking about personality development and people with developmental disabilities has remained unwavering through thirty-plus years of empirical research:

> "The individual's experiences, in large part, shape both his or her personality development and the motivational factors that characterize the individual's personality structure. By recognizing the importance of both personality-structural and cognitive-structural features, we can view the mentally retarded individual as a whole person who shares with individuals of normal intellect the same joys and aspirations as well as the same disappointments and travails" (Zigler & Burack, 1989, p.227).

In addition to saying that all people with developmental disabilities are not homogeneous in their social experiences, Zigler also suggests that "to the extent that a mentally retarded child's experiences resemble those of a normal child, the two children's personality structures will be the same" (Zigler & Burack, 1989, p.229). Zigler accepts that people with developmental disabilities are more similar to than different from the general population. He also defends the basic humanity of people with developmental disabilities.

Zigler (1975) reports that it is often the case when people with developmental disabilities are in question, that it is too readily accepted that a cognitive deficiency would make them unaffected by environmental events "known to be central in the genesis of the personality of individuals of normal intellect" (p.373). With an orientation that people with developmental disabilities manifest particular personality traits not as a consequence of their cognitive deficiency but in relation to the variations in their socialization histories, Zigler dismisses the notion that people with developmental disabilities share a universal, unvarying personality type such as dependency, anxiety or acquiescence.

According to Zigler (1975), one would expect to find variation in the personality types of people with developmental disabilities to the extent that each person had had different life experiences. This scenario, obviously, is no different for the general population. A summary of Zigler's findings concerning the personality dimensions of people with developmental disabilities (Zigler & Burack, 1989) allows it to be said that the variables which affect personality development (and this is true for the non-developmentally disabled) are social class, institutionalization and a personal history of successes and failures.

In assessing these variables in relation to people with developmental disabilities, Zigler found that people with developmental disabilities often share comparable social histories which lead to certain personality dimensions. These personality characteristics are:

- dependency on others
- approval seeking behaviour
- wariness of strangers
- outer-directed problem-solving styles
- low expectancy of success
- low aspiration level
- low ideal self-image

An abridged explanation of Zigler's (Zigler & Burack, 1989; Rosen et al., 1977) basis for the personality characteristics he delineates would include the following points:

1. Social deprivation occurring in the family history or due to institutionalization creates in people with developmental disabilities over-dependency, a heightened motivation to

receive attention and social reinforcement from adults (positive-reaction tendency) or a reluctance to interact (negative-reaction tendency).

2. Tangible social reinforcement is sought by people with developmental disabilities not due to cognitive rigidity but because the experience of social deprivation creates a heightened need for attention and approval.
3. The general lack of successful experiences in the life histories of people with developmental disabilities can lead to a low expectancy of success, a low aspiration level, helplessness and an external locus of control, meaning that one's problem-solving is characterized by outer-directedness.

A further important finding of Zigler's (1975) is that, for people with developmental disabilities, personality factors are as important in social adjustment as are cognitive factors and that personality characteristics are more influenced by environmental variables than an individual's intellectual level.

2.5.2: Additional Personality Characteristics: Helplessness, Passing and Denial and Acquiescence

Three additional personality characteristics common to people with developmental disabilities are cited in the literature: helplessness, passing and denial, and acquiescence.

Helplessness is defined as a learned behaviour associated with social experiences which label the person with a developmental disability as incompetent. It is typified by passivity or inertia and the lack of taking action to solve a problem (Rosen et al., 1977).

The person with a developmental disability whose personality is characterized by helplessness does not adequately cope with problem situations in his or her environment, typically has an external locus of control and is usually "rescued" from predicaments (Rosen et al., 1977; Ingalls, 1977).

Rosen et al. (1977) also consider the concept of helplessness to include competency factors as well as behavioural-motivational factors, such as the opportunity to make decisions for oneself or to learn about the relationship between actions and consequences. Helplessness, as defined by Rosen et al. (1977), is differentiated from the personality characteristics of (1) over-dependency on the grounds that an over-dependent person copes with problems by manipulating others to have his or her needs met, from (2) outer-directedness on the grounds that outer-directedness describes an individual's problem-solving strategy while helplessness involves a component of social maladjustment and from (3) acquiescence on the grounds that acquiescence is a predisposition to comply positively in an attempt to gain or maintain social acceptance and support.

Passing and denial are often depicted as coping or defense strategies employed to protect oneself from the social experiences of stigma, rejection, isolation and ridicule associated with a label of cognitive deficiency. They are also considered to be personality characteristics (Ingalls, 1978). People who engage in either process of pretending do so on an on-going, day-to-day basis in an attempt to delude not only others but themselves by their disposition and lifestyle. The charade of projecting a personality, lifestyle and mannerisms of a non-developmentally disabled person influences all areas of personal functioning and, no matter how successful the person might be in "passing" as a non-developmentally disabled person, he or she is contriving a false self.

The personality characteristic of **acquiescence** is a learned behaviour suggestive of a person who has not been exposed to situations in which he or she could be independent and which demanded and positively reinforced compliance (Rosen et al., 1977). These socially repressed experiences are associated with people with developmental disabilities. The acquiescent personality is further defined as a predisposition to comply or respond affirmatively, even when it is not in the person's best interest to do so (Rosen, Floor & Zisfein, 1973; Rosen et al., 1977).

Acquiescence is thought to develop in response to parental and societal norms that condition children, regardless of the condition of developmental disability, to display submissive, uncritical and compliant behaviours (Rosen et al., 1973).

The person with a developmental disability who has an acquiescent personality may use an acquiescent response as a way to hide his or her ignorance, as an automatic answering strategy or as a means to gain social approval (Sigelman, Budd, Spanhel & Schoenrock, 1981).

2.6: Self-Concept

While self-concept is considered to have primary importance within general personality theory, it has been little researched with respect to people with developmental disabilities (Zigler & Burack, 1989). Zigler and Burack (1989) suggest that this lack of interest is counter to the expectation that negative life experiences of people with developmental disabilities would deeply affect their self-concepts in a negative manner. Similarly, Kauffman (1994) states the view that the negative social experiences associated with growing up developmentally disabled in a non-developmentally disabled world is likely to "create a self-concept perilously riddled with losses that saturate the mentally retarded person's sense of identity" (p.265).

Empirical research suggests that children with developmental disabilities have lower ideal self-images than their non-developmentally disabled peers (Collins, Burger & Doherty, 1970; Wilson, 1970; Rosen et al., 1977: Zigler & Burack, 1989), with those who were separated at an early age from their parents expressing greater negative self-attitudes (Rosen et al., 1977).

However, the condition of a developmental disability has not been shown to have any effect in and of itself on self-concept (Wilson, 1970) and it is reported to vary independently of I.Q. (Wilson, 1970; Rosen et al., 1977).

The commonly accepted definition of self-concept — a reflection of the ways in which one is treated by significant others (Jahoda et al., 1988) — suggests that the main variable which affects the development of self-concept is interpersonal experiences (Maloney & Ward, 1979; Zetlin & Turner, 1984; Applegate & Barol, 1989).

As self-concept is a socio-personal characteristic, meaning that it is influenced by a number of developmental, situational and subjective variables (Cegelka & Herbert, 1982), additional influences on self-concept of people with developmental disabilities have been hypothesized. Specifically, the effects of sheltered or segregated living, self-doubt, a disproportionate amount of failure experiences/lack of success and the effects of the social stigma and marginal status (Langness & Levine, 1986; Zetlin & Turner, 1988).

Moreover, Zetlin's and Turner's (1988) work on the self-concept of people with developmental disabilities extends to identifying "salient domains" from which adults with developmental disabilities draw upon to form self-conceptions. Those domains are: work, social conformity, social dependency, activities or possessions, heterosexual relationships and relationships with family and friends. Baroff (1991) similarly refers to domains from which self-esteem grows. He presents self-esteem as growing out of three subneeds: intimacy, success and autonomy.

Assessment of the effects of certain situations on self-concept, which are particular to people with developmental disabilities, such as institutionalization, segregated school placements and mainstreaming programs, have achieved, at best, conflicting results (Wilson, 1970; Cegelka & Herbert, 1982; Zetlin & Turner, 1988).

To return to the main variable of self-concept — interpersonal experience — it is held that when developmental lags are noticed by a child's caretakers, the caretakers' acceptance of the child as being delayed will likely cause a modified response to the child which is rejecting, overprotective or indulgent (Maloney & Ward, 1979). Following this reasoning, the type of self-concept that a child with a developmental disability develops is dependent upon what he or she learns about himself or herself via the responses of others (Maloney & Ward, 1979). As Zetlin's and Turner's (1984) research suggests, parental practices and expectations emerge as the primary influence on the adult adjustment and the attitudes toward personal disability which are developed by people with developmental disabilities.

If the self-concept is a reflection or an integration of the responses one is receiving from significant others concerning functioning and abilities, the question arises, can self-concept fluctuate with changes in social environment and others' evaluations? Jahoda et al. (1988) report that the self-concepts of people with developmental disabilities are not "static over different contexts and over time" (p.106) and that a mutually interdependent relationship exists between an individual's self-concept and his or her social world.

Similarly, Zetlin and Turner (1984) and Cegelka and Herbert (1982) make reference to self-concept as relational to the environment. In particular, Zetlin and Turner (1984) refer to "situational identities" (p.117). This means that people with developmental disabilities may don a certain self-identity depending on audience, setting or circumstance. Cegelka and Herbert (1982) refer to self-concept as being "both generalized and specific to situations, people and events" (p.161).

Suggesting that more permanent shifts in self-concept do occur, Zetlin and Turner (1984) report that changes in self-concept can result from maturation and gaining confidence through experiences or achievements. While the self-concept of a person with a developmental disability may fluctuate, Zetlin's and Turner's research suggests a link between past environment and social experiences and core, distinguishing patterns of self-attitudes which remain identifiable and stable.

To the extent that people with developmental disabilities live within a "handicapped world" where social contact is almost exclusively with other people with developmental disabilities (Zetlin & Turner, 1984), interacting with the mainstream community can necessitate defending one's self-concept as "non-retarded." Four protective coping strategies, similar to Edgerton's cloak of competence concept, are reported (Zetlin & Turner, 1984):

- acceptance of being labeled developmentally disabled but comparing oneself favourably to lower functioning people;
- denying and attributing difficulties and failures to prejudice and conspiracy;

- avoiding and accepting that no one challenging their non-developmentally disabled identity as proof of normalcy;
- redefining and attributing difficulties and failures to less stigmatizing conditions.

It is noted that while a person with a developmental disability may be aware of being assigned a "global handicapped status" (Jahoda et al., 1988, p.113), a handicapped identity may not be internalized. This depends whether there is awareness of one's status as, foremost, a human being, and that a stereotyped handicapped status is being imposed as a result of social prejudice.

2.6.1: Self-Concept Profile

It can be inferred from the preceding section that people with developmental disabilities, giving consideration to their typical social experiences of parental restriction, social segregation, peer rejection and/or ideal-self discrepancies, will tend to have self-concepts which are defended and vulnerable (Edgerton, 1967, cited in Wilson, 1970).

Self-concepts are more attributable to contextual social histories and life events than to the intrinsic qualities of the condition of developmental disability. That negative self-concepts are, nonetheless, more prevalent in people with developmental disabilities is suggestive that people with developmental disabilities have a unique self-concept profile.

Two studies which provide a self-concept profile have explored adolescence, developmental disability and the development of self-concept are Levy-Shiff et al. (1990) and Collins et al. (1970). The life-cycle stage of adolescence is significant because during adolescence, according to an Eriksonian view, one works through the subjective task of forming a personal identity (Erikson, 1980). This means the development of the conscious feeling of individual uniqueness which is in agreement with the ideals of one's social group (Wolff, 1989).

Levy-Shiff et al. (1990) suggest that relative to non-developmentally disabled adolescents, adolescents with developmental disabilities display a "unique profile of identity" (p.546) including thinking of themselves as having (1) lives which are meaningless and uninteresting; (2) unclear sense of body image and body boundaries; (3) an uncertain sense of mastery and self-control over feelings, acts and behaviours.

Collins et al. (1970) suggest that adolescents with developmental disabilities have more negative self-concepts and low self-esteem relative to adolescents without developmental disabilities. As these researchers explain, they unexpectedly found that adolescents without developmental disabilities also have negative self-conceptions and low self-esteem but to a less negative degree. The dimensions of self-concept that Collins et al. (1970) included in their study were: self-satisfaction, behaviour, physical self, personal self, self-criticism, identity, social self and moral-ethical self. There was no significant difference between adolescents with or without developmental disabilities on the first four dimensions.

2.7: Linking Social Experience, Personality Development and Self-Concept

Most of the cited literature on social experiences, personality development and self-concept dates from the late 1960s to the late 1980s. During this time Ontario was not static with regard to social-cultural changes and people with developmental disabilities.

Ontario has initiated "progressive" changes to amend its treatment of people with developmental disabilities. Two such changes are a policy of normalization and deinstitutionalization. These attempts do not invalidate the cited findings or mean that the social experiences of people with developmental disabilities have changed for the better. On the contrary, these en masse political changes expose people with developmental disabilities to new stresses, challenges and social expectations, for which, most likely, they are unprepared (Ghaziuddin, 1988).

At the present time, the mental health profiles of people with developmental disabilities, including the dimensions of personality and self-concept, continue to project the themes of rejection, isolation, dependency, defensiveness and attention and nurturance seeking (MARC, 1995). This suggests that social experiences and, therefore, social tolerance is still tethered to the late 1960s.

Discussion of the atypical social experiences, personality development and self-concept of people with developmental disabilities has demonstrated that the atypical social experiences of people with developmental disabilities can create emotional and psychological stress which can affect the development of personality and self-concept and create a unique personal history of circumstantial loss.

The next section addresses the understanding of death and the grief reactions of people with developmental disabilities.

2.8: Understanding the Concept of Death

The most often cited research which assesses grief reactions of people with developmental disabilities is by Harper and Wadsworth (1991, 1993). However, they did not initially set out to explore grief. Their finding that people with developmental disabilities have grief reactions materialized as an outgrowth of a longitudinal study regarding older adults with developmental disabilities and the issues of aging, loss of skills and the use of psychoactive medications. The work of Harper and Wadsworth, while providing overdue recognition for the grief of people with developmental disabilities, suggests they assumed, at least initially, that grief and developmental disability were not related domains.

While loss and grief are recognized to be universal, human experiences, (Deutsch, 1985; Yanok & Beifus, 1993), Howell (1989) further states that this is true "irrespective of one's level of cognitive development and capability" (p.328). Thoughts on why the issue of grief and people with developmental disabilities has been little researched include:

- developmental disability and death are the two biggest taboo subjects in North American and British society (Emerson, 1977; Kloeppel & Hollins, 1989);
- the assumption that people with developmental disabilities do not have the same feelings as the general population and, therefore, lack the ability to experience grief (Deutsch, 1985; Oswin, 1989);
- people with developmental disabilities are unable to form the basic emotional bonds and intimate personal relationships, that if severed, would be experienced as personal loss (Deutsch, 1985; Yanok & Beifus, 1993);

- people with developmental disabilities have enough problems already and need to be spared from "unnecessary" stress (Deutsch, 1985);
- and people with developmental disabilities, regardless of their chronological age, are considered to be cognitively incapable of understanding the three essential death concepts of irreversibility, universality and inevitability (Deutsch, 1985; Yanok & Beifus, 1993).

While Howell (1989) believes that no matter one's level of cognitive development some level of understanding about personal loss and grief will be present, this is not documented in the literature. However, the existing research does suggest a positive relationship between understanding of death concepts and people with mild to moderate "mental retardation."

2.8.1: Relationship Between Age and Understanding of Death

Initial hypotheses regarding the understanding of the concept of death and people with developmental disabilities have been based on research documenting the developmental progression of the understanding of death in children without developmental disabilities (Wadsworth & Harper, 1991). The empirical findings of Nagy (1948), Anthony (1967, cited in Sternlicht, 1980), Kastenbaum (1967, cited in Sternlicht, 1980) and Koocher (1973) regarding the "normal" child's conception of death agree that the conception of death is directly related to chronological aging. However, this finding has not been presumed to hold true for people with developmental disabilities.

The first to research the understanding of the concept of death in people with developmental disabilities were Sternlicht (1980), who tested children with developmental disabilities and Bihm and Elliott (1982) who tested adults with developmental disabilities to see if Sternlicht's results could be generalized. These researchers replicated Koocher's (1973) study in that they analyzed the concept of death in people with developmental disabilities from a cognitive-developmental framework applying Piagetian cognitive levels of development from preoperational to formal operational reasoning.

The hypothesis being tested was whether conceptions of death in people with developmental disabilities increased as levels of cognitive development increase from preoperational to concrete-operational to formal-operational reasoning, as is the case for children of average intelligence. As Seltzer (1989) suggests, this increase in cognitive level does not necessarily indicate that a person understands more about death and/or aging but that the concept of death is understood in a qualitatively different manner; that is, the person attributes different meanings to death.

Sternlicht's finding was that cognitive level, not age alone, determines the understanding of the concept of death in a child with a developmental disability. Children with developmental disabilities who function at the concrete operational stage of reasoning were found to have a more realistic and mature understanding of death than those at a preoperational stage (Wadsworth & Harper, 1991). Similarly, Bihm and Elliott (1982) found a relationship between Piagetian cognitive level and an understanding of death, with those with a concrete-operational level of reasoning possessing a more realistic conception of death as opposed to those at a preoperational level.

These two research studies suggest that for people with developmental disabilities, age and the concept of death are not directly related. Rather cognitive level is a better gauge of the understanding of death (Bihm & Elliott, 1982; Wadsworth & Harper, 1991).

It is interesting to note that Bihm and Elliott (1982) close their article by pointing out that their structured study focused on "cognitive" rather than "emotional" aspects of understanding death. They make the assertion that, despite cognitive limitations, people with developmental disabilities express emotional concerns about death the same as people of average intelligence.

2.8.2: Additional Research

McEvoy (1989) and Lipe-Goodson and Goebel (1983) provide additional research which addresses an understanding of death and developmental disability and which underscores the "humanness" of people with developmental disabilities.

McEvoy (1989) found that people with developmental disabilities are capable of expressing their opinions on death through open-ended questioning. McEvoy studied adults with developmental disabilities and adopted a cognitive-developmental approach to explore their understanding of the three elements of death which reflect a mature understanding: irreversibility, universality and non-functionality. McEvoy's findings were that people with developmental disabilities with "higher abilities" (James, 1995, p.77) in the areas of communication, self-care and community skills had more mature understandings of death. McEvoy's findings, however, were not significant for age, sex or previous experience with death.

Lipe-Goodson and Goebel (1983) demonstrated that when assessing people with developmental disabilities in regards to their ability to understand death, one needs to allow for individual differences in life experience. Lipe-Goodson's and Goebel's findings suggest that while developmental age and life experience tend to increase proportionately with chronological age in people of average intelligence, in people with developmental disabilities this relationship is not true.

Lipe-Goodson and Goebel (1983) suggest that there is a strong relationship between age and the ability to conceptualize death, meaning that accrued life experience acquired through aging may be a more important variable in the development of understanding of death concepts in people with developmental disabilities than is cognitive functioning (James, 1995). Lipe-Goodson's and Goebel's study suggests that people with developmental disabilities who have exposure to the subject of death may understand death in a manner which would be characteristic of people with higher cognitive abilities.

Lipe-Goodson's and Goebel's (1983) work also suggests that cognitive understanding of death and loss in people with developmental disabilities can reflect cognitive knowledge as well as cultural, family or religious experiences (Harper & Wadsworth, 1993).

2.9: Death Education and Grief Counseling

The literature on conceptions of death and people with developmental disabilities also contains a related reference to the development of an understanding of death through death education (Duetsch, 1985; Kloeppel & Hollins, 1989; Yanok & Beifus, 1993).

Yanok and Beifus (1993), in recognizing that death education and grief counseling are rarely a part of habilitation programs for people with developmental disabilities, designed a curriculum called Communicating About Loss & Mourning (CALM). They administered it in eight sessions to people with "moderate mental retardation." Results indicated that the experimental group demonstrated more mature understandings of death than the control group who did not receive instruction. Yanok's and Beifus' work suggests that death education would be beneficial to people with developmental disabilities.

In a seminal article on grief and developmental disabilities, Deutsch (1985) comments upon the relevance of death education for people with developmental disabilities. He suggests that a curriculum should include: information about the initial impact of the death of a significant other; learning about funeral rituals; identifying resources and support people; and educating about four specific tasks of grieving - accepting the reality of a loss, experiencing emotional pain, adjusting to life without the deceased and investing in new relationships.

2.10: Universal Concern of Grief

Similar to Zigler's and Burack's (1989) appreciation of the social and personality aspects of people with developmental disabilities, Smith (1975), in reporting on theoretical approaches to grief in the general population, comments that too much emphasis has been placed on the biological elements of grief responses and that the social context in which grief occurs leads to a fuller understanding of grief reactions.

Most authors report that grief reactions in people with developmental disabilities, except for the most profoundly developmentally disabled (McLoughlin, 1986; Harper & Wadsworth, 1993), are more similar to than different from those of the general population (Graffam, 1984; Oswin, 1985; McLoughlin, 1986; Carder, 1987; McDaniel, 1989; Wadsworth and Harper, 1991, 1993; Hollins, 1995; James, 1995).

However, it is also reported that grief in people with developmental disabilities is often misinterpreted to be just "extra-difficult behaviour" (Oswin, 1985, p.198) associated with their developmental disability rather than the normal behaviour of a person who is grieving (Harper & Wadsworth, 1993). Such misinterpretation is thought to be due to basic unfamiliarity with normal grief reactions in people with developmental disabilities. Their limited cognitive, verbal and social functioning often leads to the expression of grief through nonverbal, overt behaviour (Emerson, 1977) which may not be interpreted by others as grief as it is not the typical, expected reaction of a grieving person (Oswin, 1985; Ghaziuddin, 1988; Harper & Wadsworth, 1993).

Rather than debate the ability of people with developmental disabilities to grieve, several authors point out the absurdity of dismissing people with developmental disabilities as feeling, sensate human beings. Oswin (1992, cited in James, 1995) suggests that the important question to ask of any person is not whether his or her grief is "normal" but rather "What might be expected for this sort of person with this type of loss?" (p.74).

Seltzer (1989) contributes the thinking that limited cognitive ability does not preempt loss from occurring in one's life or feelings of grief associated with loss. Huston

(1992) poignantly states the reminder that people with developmental disabilities may not "think as fast but they feel as deeply" (p.11).

2.10.1: Grief Reactions

Despite similarities in grief reactions between people with developmental disabilities and the general population differences exists. Ghaziuddin's (1988) research on the role of life events for people with developmental disabilities reveals why, for some. responses to loss may be atypical. Ghaziuddin found that commonplace life events can acquire immense psychological meaning and significance for some people with developmental disabilities because: (1) brain damage can distort perception, discrimination and abstraction abilities; (2) emotional stress can cause cognitive disorganization and deterioration in behavioural and intellectual functioning; (3) and life events are more instrumental in influencing the behaviour of people with "mild mental retardation."

Golding (1991) also notes possible internal and external reasons why a person with a developmental disability may respond "differently" (p.17) in his or her grief reaction. Internal reasons are poor attention, poor understanding of the concept of death, poor abstraction and poor ability to express emotions verbally. Her external reasons are: being viewed as a child and in need of protection, misinformed about death, multiple losses, social rules and being diagnosed rather than understood.

Just as with the general population, grief reactions in people with developmental disabilities are dependent upon: personal history, personality, prior experiences with death, relationship with the deceased, circumstances of the death (James, 1995); present life context (Hollins, 1995); how the death was disclosed; and the additional losses provoked by the death, especially the death of a caretaker with whom they lived, such as leaving one's home, family and neighbourhood and moving to a residential placement (Oswin, 1985, 1990, 1991).

In consideration of the above, people with developmental disabilities, relative to the general population, are reported to:

- experience the same phases of grief (Huston, 1982; Wadsworth & Harper, 1991);
- express grief through feelings (sadness, anger, fear, panic, shock, anxiety, loneliness, fatigue, freedom) (Oswin, 1990; Harper & Wadsworth, 1993);
- experience physical sensations (lack of energy, sensory sensitivity, tightness in chest, hollowness in stomach, dry mouth) (Harper & Wadsworth, 1993);
- experience cognitions (disbelief, confusion, preoccupation, hallucinations, sense of deceased's presence) and behaviours (disturbances in sleeping, eating and speech, social withdrawal, absent-mindedness, avoiding or obsessing over reminders of the deceased, aggression, self-injury, crying, calling-out and searching) which can delay the acceptance of loss and display of grief (Harper & Wadsworth, 1993; Hollins, 1995; James, 1995; Moddia & Chung, 1995).
- experience grief one year after the death (Harper & Wadsworth, 1993).

2.10.2: Causing Harm

Typically, grief responses in people with developmental disabilities are treated by family or professionals in ways which can ultimately cause, unintentionally, confusion and harm (Oswin, 1988; Wadsworth & Harper, 1991). The following situations are said to be routinely experienced by people with developmental disabilities:

- a caretaker denies that a death occurred and says that the deceased went on a holiday or away to work or uses confusing euphemisms such as "went to sleep" (Ray, 1978; McLoughlin, 1986; Carder, 1987; Harper & Wadsworth, 1993);
- exclusion from the rituals surrounding the death which are really in themselves very supportive (Oswin, 1985; McLoughlin, 1986; Wadsworth & Harper, 1991);
- minimization of the impact and meaning of the death (Wadsworth & Harper, 1991);
- misinterpreting and/or ignoring behavioural changes as signs of grief (Oswin, 1985; Wadsworth & Harper, 1991; Kauffman 1994);
- treating the unrecognized grief reactions with behavioural restrictions and/or medication (Oswin, 1988; Wadsworth & Harper, 1991; Moddia & Chung, 1995).

Such protective, yet harmful treatment can raise concerns of abandonment and exclusion (McDaniel, 1989; Wadsworth & Harper, 1991; Kauffman, 1994); responsibility and guilt (Wadsworth & Harper, 1991; Chambers & Martin, 1993); separation anxiety and fears of not being cared for and of dying (Seltzer, 1989; Wadsworth & Harper, 1991); and behaviours of searching for and waiting for the deceased person to return from their "journey" or "job" (James, 1995, p.77).

Several authors comment upon how the protection from death and grief rather than the reality of the death results in more harm such as complicating grief reactions and causing psychiatric problems (Day, 1985; Oswin, 1985; Kloeppel & Hollins, 1989; Chambers & Martin, 1993; Wadsworth & Harper, 1991, 1993).

Noted also is that the situation following a death, especially if the deceased was a caretaker, is one of multiple loss and disruption for people with developmental disabilities. Stresses such as changes in living arrangements, daily routines, availability of support and attention (Kloeppel & Hollins, 1989) and loss of family, pets and neighbourhood, which all happen without permission or agreement from the person with a developmental disability, are said to make the effects of bereavement, in terms of a life event, more significant to people with developmental disabilities (McLoughlin, 1986; Wadsworth & Harper, 1991).

Since these multiple changes can produce a snowballing effect, death, with its accompanying profound stresses, is regarded as a precipitant factor in the development of psychiatric problems in people with developmental disabilities (Emerson, 1977; Day, 1985; McLoughlin, 1986; Wadsworth & Harper, 1991, 1993). A death can stir up past unprocessed losses associated with atypical social experiences (Kauffman, 1994); grief can be misinterpreted or ignored; intellectual and communication abilities can impede expressing grief; or overwhelming changes and stress can be encountered after the death of a significant other.

CHAPTER THREE

Methodology

3.1: Theoretical Perspective and Design

A qualitative methodology was chosen as the thrust of this study was to collect descriptive information about the social experiences and personal loss histories of people with developmental disabilities, in their own words and from their own perspectives. That people with developmental disabilities have perspectives on their lives and situations, have feelings and emotions and subjectively experience the world similar to anyone else has been documented by Bogdan and Taylor (1982).

This study explored how the awareness of being regarded and treated as intellectually and socially sub-average affects personality development and the self-concept of people with developmental disabilities and, ultimately, the state from which grief is approached in the event of a significant other's death.

Importantly, this study's qualitative approach did not reduce the participants[1] to "isolated variables" (Bogdan & Taylor, 1975, p.4). Instead, it allowed a holistic view of people with developmental disabilities as a part of the society which has influenced their personal development and which has possibly put them at a disadvantage for facing the universal concern of grief. Moreover, a qualitative approach allowed for the exploration of

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[1] The term "participant" is used to refer to the participants with developmental disabilities. As parents and siblings also were participants in this study, they will be differentiated by specific reference to them.

concepts, such as grief and loss, whose "essence" (Bogdan & Taylor, 1975, p.5) can be lost in a quantitative approach.

The exploratory nature of this study lent itself to the qualitative technique of semi-structured interviewing. Semi-structured interviewing (five open-ended questions made suitable for language preferences and needs) was used to elicit participants' information. Specifically, their perspectives on the social experience of having a developmental disability; their personal losses associated with having a developmental disability; and how their awareness of having a developmental disability and experiencing differential treatment on the basis of their disability has affected personal development. Details of the semi-structured interview schedule are included in the instrumentation section and Appendix C.

A semi-structured interview technique, with its purpose being to access participants' perspectives, rather than to "put things" (Merriam, 1988, p.73) into their minds, as can happen with structured interview designs, complemented this study's aspirations. Allowing participants to speak about and detail their own experiences rather than conduct a study where they were only spoken about and regarded as separate categories of humans is, as Bogdan and Taylor (1982) comment, a rare occurrence.

A standard recording method was also used during interviewing to collect personal-history information. Specifically, the creation of a life event document. In creating the pen and paper life event documents, the participants had full control over where their disclosed information about their social and life events was placed on the document. Life event documents were a means to enhancing the involvement of the participants during interviewing. As the participants each received a copy of their life event document at the end of interviewing, the documents also served as a means for giving the participants a tangible return for their participation. A sample life event document and the participants life event documents are in Appendix D.

In seeking to understand developmental disability and grief from the perspective of people with developmental disabilities a phenomenological theoretical orientation was adopted (Bogdan & Taylor, 1975). A phenomenological perspective seeks to "understand human behaviour from the actor's own frame of reference" (Bogdan & Taylor, 1975, p.2). This study's semi-structured interviewing, coupled with the creation of life event documents allowed each participant's "loss-history" (Lendrum & Syme, 1992, p.71) to emerge and also allowed for a phenomenological understanding of developmental disability and grief.

3.2: Population Sample

Participants included fourteen people with developmental disabilities. Participation of a parent[2] or a sibling was desirable but optional. Seven participants had family members participant; five parents and three sisters were included. Involvement of parents and siblings was for the purpose of gaining their perspectives on the social and life experiences of the related person with a developmental disability. All but one participant was referred through an agency-based personal network system which included four agencies providing

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[2] This study made provision for the term "parent" to include a biological or a past or present legal guardian who had acted as a caretaker.

residential, vocational, and/or family support services to people with developmental disabilities. One participant, who was featured in a local newspaper article, was recruited through the mail; he was sent a letter of invitation to participate. Participants came from three geographic areas: Kitchener-Waterloo, Cambridge and New Hamburg.

Use of an agency-based personal network system helped to ensure that a participant's selection would be determined by a service provider who knew the individual. Also, it was important that participants had continuing support when the interviewing was finished in case they wanted or needed to further discuss issues raised during the interviewing. Detailed descriptions of all participants, parents, and siblings appear in the next chapter.

The only criterion of the participants was that each had to have experienced the death of at least one significant other. No restrictions where placed on when the death had occurred. If the death was recent, the supporting agency was asked to consider the appropriateness of an individual's involvement. If a death occurred in the distant past, the supporting agency was asked to consider an individual's ability for memory recall.

On the issue of long-term memory recall, this study acknowledges Turnure's (1991) work which documents that the long-term memory capacity of young "mildly handicapped is intact and functions within normal ranges" (p.212). Turnure (1991) concludes that "mildly retarded" people appear to have sufficient implicit and explicit memory systems and he reports no instances of consistently low profiles of performance found in those with memory disorders.

The age of the participants was not a selection factor. However, it was presumed that children would be less ideal than adults for this study as they might have fewer life events and social experiences to cite.

The degree of developmental disability was only a consideration in terms of it impeding an interview. It is acknowledged that the extent to which a person's degree of developmental disability precludes him or her from speaking for himself or herself is a subjective matter. I believe that it is not so much a matter of a person with a developmental disability being able to "speak" but one of my being able to "hear" (Stanovich & Stanovich, 1979; Bogdan & Taylor, 1982).

3.3: Means of Information Collection

Two issues were raised about collecting personal information from people with developmental disabilities: age of legal consent and the capacity to give informed consent. A third related issue was the appropriateness of making the participation of adults with developmental disabilities dependent upon their parents' consent. These issues necessitated the development of two procedures for obtaining consent.

The procedure of obtaining direct consent and guardian permission was available for those whose developmental disability precluded the capacity to engage in rational decision-making or for those under the age of eighteen. A second procedure of direct consent only was available for those with the capacity to engage in rational-decision making. Determining "capacity" was the responsibility of the referring agencies.

Consent Form I was prepared for the guardian who would give permission to participate for the person with a developmental disability whose level of disability precluded rational decision-making or for those under eighteen. This form also requested the participation of the guardian. Provision for the guardian who declined personal participation but gave permission for the person with the developmental disability to participate was made in Consent Form II.

Consent form III was prepared for those eighteen and older and able to give direct consent. Consent Form III also asked for permission to contact a parent or sibling for the purpose of learning more about a participant's social and life experiences. If a parent or sibling agreed to participate, he or she was asked to sign Consent Form IV.

In addition, if participants could not give written consent their verbal consent, witnessed by a third party, was accepted. This study's four consent forms are in Appendix A.

Thirteen participants gave direct consent and signed Consent Form III. The parents and siblings who also participated signed Consent Form IV. One participant chose to give witnessed, verbal consent, which was recorded on Consent form III.

All participants in this study, including parents and siblings, were first contacted about this study by the agency they were affiliated with. I only met with the participants, parents and siblings after each indicated an interest, through the affiliated agency, to do so. During an initial meeting prior to the start of interviewing, written consent was obtained from the participants, parents and siblings to audio tape and then transcribe their interviews. All audio tapes were transcribed by a professional transcriber.

Participants were individually interviewed in no more than two one-hour long interviews. One participant was interviewed one time only due to her direct-care staff's concern that this person was "acting out" following the first interview. Provision was made to interview in no more than four, one-to-one and one-half hour long interviews.

I held two additional meetings with each participant in which information was not collected. These two meetings consisted of the initial meeting to get acquainted and a final meeting for closure. The need for these two additional meetings emerged from my sensitivity to the participants' needs for boundaries concerning my relationship with them – that I was a researcher and not a short-term or long-term friend. My personal experience of working with people with developmental disabilities allowed me to foresee the potential for my presence and familiarity to be misinterpreted as signs of my friendship.

All interviews in which information was collected were audio taped and conducted at the participants' residences. One participant, the same who chose to give verbal consent, chose not to be audio taped but did permit note-taking. One participant asked to meet at the university campus.

Parents and siblings were interviewed separately from the related participant. They participated in a single one-to-one and one-half hour long interview which was conducted at their homes. Information from parents and siblings was collected after I had interviewed the related participant, or during the same time period. The parents' and siblings' interviews included the same semi-structured interview schedule as for the participants with developmental disabilities (Appendix C). They were also asked to allow me to record on a pen and paper life event document the social and life events of the related participant which they thought significant. The life event documents served the same purpose of enhancing the parents and siblings involvement during interviewing. These documents were retained for their data collection value and were not returned.

I informed agencies, parents, siblings and the participants that the participant could chose to be accompanied at the interview by a support person, who was not a parent or sibling. This support person functioned as either a presence of familiarity or facilitated communication between the participant and myself. Support people were present for four of the fourteen participants for the purpose of ensuring meaningful dialogue.

During the initial meeting with the referred participants it was explained to each why he or she had been referred for this study. I informed the participants that I wanted to talk with them because they had experienced the death of a significant other and because they were labeled with a disability. During my initial meeting with the referred participants, as with their parents or siblings, I inquired about preferred disability terminology and subsequently used this.

As Royse (1991) suggests, the qualitative researcher is in the role of "learner" (p.222) and, as such, during interviewing, I allowed the participants to step into the their rightful role as experts on their lives; to be the "teacher" helping me to understand their social and life experiences and the impact of those experiences on their personal development. All participants took seriously their role as "teacher" and appeared to receive personal satisfaction from being referred to as such.

As a matter of courtesy, the participants, parents and siblings, support people and referring agencies received a thank-you letter.

No deception or manipulation was involved in this study. All participants, parents and siblings were made aware that they could refuse to answer any questions or withdraw their participation at any time. Every effort was made to be sensitive to participants' vulnerabilities. All participants, parents, siblings and referring agencies were offered a summary of this research report.

Interviews were held from January to May, 1996. Transcriptions were completed following the interviews. Analyses of the information occurred in July and August, 1996.

3.4: Instrumentation

An interview schedule consisting of two parts was used in this study. Part A outlined demographic information for the participants, parents and siblings (Appendix B). Demographic information included age, sex, ethnicity, religious affiliation, family composition and relationship to the deceased. Additional information was collected for the participants only. This included formal diagnosis, age at diagnosis, developmental age, education, and type of residence.

Part B was a semi-structured interview schedule (Appendix C) consisting of five questions developed from a review of the literature pertaining to developmental disability and: social experiences, social comparison, personality and self-concept characteristics, and grief. As this study intended to allow people with developmental disabilities to speak for themselves these questions were used on a "need-to" basis. I did not ask each of the five questions if the participant, including the parents and siblings, addressed the subject matter spontaneously.

The first and second question probed for social and life experiences and history of necessary and circumstantial losses. The third question probed for an awareness of differential treatment based on the condition of having a developmental disability. The fourth question probed for self-evaluation. The fifth question addressed experiences with death and grief. As participants varied in their receptive and expressive verbal skills, I adopted their language preferences and, when a question from the semi-structured interview was used, I conveyed the question in wording which was the most meaningful to the participant.

From the information each participant disclosed in their interviews, a picture of his or her phenomenological world was constructed. Their subjective recounting of their social and life experiences and their interactions with others gave insight into their personality and self-concept characteristics. My understanding of the participants' social experiences, their personality and self-concept characteristics, and their experiences with death and grief was enhanced by relating their information to the cited literature. Interviews with parents and siblings were valuable for the historical information provided. Interview findings are reported in the next chapter.

3.5: Response Validity

Of concern in studies among the general population, and particularly in studies whose primary informants have a cognitive disability, is the issue of response validity: the ability of the respondent to provide valid information in response to questions (Sigelman, Budd, Winer, Schoenrock & Martin, 1982; McEvoy, 1989). Flynn (1986) notes that "the ability to respond to a question is partially a function of intelligence" (p.369) and that this ability is enhanced by the mode of questioning.

While interviewing the participants, I was aware of and sensitive to the issues of response bias. In regards to the type of questioning which is most practical in terms of level of responsiveness, Flynn's (1986) review of the literature suggests the following: (1) "yes/no" questions are the most easily answered, but there is a tendency for people with developmentally disabilities to acquiesce; that is, to respond affirmatively regardless of a question's content which invalidates the response; (2) open-ended questions are preferred on the grounds of validity but they typically yield a low response due to poor comprehension of the question; and (3) verbal "either/or" questions are difficult for people with developmental disabilities to answer but yield a more valid response than "yes/no" questions.

Flynn's comparison of alternate questioning strategies is augmented by Sigelman et al.'s (1982) evaluation which found: (1) open-ended questions are inadequate in terms of validity; (2) the use of examples and the probe "What else?" does not improve validity in open-ended questions; and (3) open-ended questions with a closed-format such as a "yes/no" checklist were well responded to but validity was compromised by acquiescence.

Sigelman et al. (1982) concluded that verbal and pictorial multiple choice questions are potentially the most useful and a valid alternative to open-ended questions and that open-ended questions, given their limited response rate and bias towards underreporting of activities, are preferable to yes/no checklists on the grounds of validity.

Similar to Flynn's (1986) findings about the use of closed, "yes/no" questioning formats, Edgerton (1984) who adopts an holistic approach in his studies of people with developmental disabilities cautions that the direct questioning of standardized interviews yields trivial or socially desirable answers from people with developmental disabilities.

While open-ended questions are the preferred mode of interviewing (Flynn, 1986; Sigelman et al., 1982; Lovett & Harris, 1987), I did take steps to enhance response validity. As suggested by Sigelman, Schoenrock, Spanhel, Hromas, Winer, Budd and Martin (1980), I addressed the issue of response validity by (1) rephrasing questions when possible within the interviews to monitor for contradictions in answers and, (2) when possible, information was compared with a second informant: the referring agency, parent or sibling. As Sigelman et al. (1980) suggest, disagreement between the participant and a second informant was taken as an indicator of response validity not as a judgment that the participant was the party with the invalid information.

Further, guidelines pertaining to interviewing people with developmental disabilities formed by Flynn (1986) were, in part, followed: (1) interviews were audio taped to avoid inducing anxiety by writing during interviews; (2) interviews were conducted in private, except for the requested presence of a support person; (3) interviews were completed in participants' residences; (4) and interviews were conducted in an informal, non-threatening, conversational manner.

In terms of level of intellectual disability, interviewing people with intellectual disabilities in the "severe" range are suspect in terms of validity, while people with "moderate" and "mild" ranges of intellectual disability are considered to have greater responsiveness and response validity. The contention of Sigelman et. al (1980) that an uncritical acceptance of the interview responses from participants with developmental disabilities is imprudent, is considered in this study.

3.6: Ethical Considerations

Ethical considerations included in this research were: the ethics of recruiting participants to be interviewed; the ethics of obtaining voluntary, informed consent; the ethics of maintaining confidentiality of the information; the ethics of sharing results with participants; the ethics of causing no harm; and the ethics of the boundary between grief research and therapy (Parkes, 1995; Cook, 1995; Rosenblatt, 1995).

3.6.1: Procedure for Recruiting Participants

The following procedure was used to recruit participants:

1. Participants were obtained through an agency-based personal network system. This method decreased the chance of coercion and deception as it allowed for an intermediary.

3.6.2: Plan for Obtaining Informed Consent

Cook (1995) notes three aspects to voluntary consent: voluntariness, information and comprehension. The following plan for obtaining consent respected these three points. As previously referred to in section 3.3, two protocols were developed to obtain consent based on legal age and capacity to give consent. As all fourteen participants gave direct consent, only the procedure prepared for this group is presented.

1. The supporting agency explained my role and gave a brief overview of the proposed research to the selected participants.
2. If selected participants were interested in this study, I arranged an initial meeting through their service provider.
3. During an initial meeting with the selected participants, I explained in appropriate language the purpose of the study, what would be involved in participating, issues of confidentiality and consent and the right to withdraw at any time. If they chose to participate, an interview time and place was established. If they chose not to participate they were thanked for their time.
4. I discussed the research and obtained consent (Consent Form III) prior to the start of interviewing. I also asked for consent to contact a parent or sibling to ask for their participation. If such consent was given, I contacted the parent/sibling to explain the research. A parent/sibling who agreed to participate was then asked to sign Consent Form IV.

3.6.3: Procedures to Ensure Confidentiality of Information

The following procedures were used to ensure confidentiality of the information:

1. Audio tapes, computer-disc copies and hard copies of interviews were kept in a locked environment.
2. Audio tapes were transcribed by a professional transcriber who was aware of issues of confidentiality.
3. Initials only were used in the transcriptions.
4. Audio tapes and all copies of transcriptions were destroyed upon the completion of the study.
5. Neither real names nor initials were used in the final research report.
6. Permission was obtained to use direct quotes.
7. Demographic information was reported using pseudonyms.
8. Content of interviews was analyzed for themes, categories and reflections on the overall study questions.

3.6.4: Feedback and Sharing Results with Participants

Feedback was given to participants as follows:

1. I promptly answered any questions, in writing, if requested.
2. A summary of the study results was offered to participants, parents, siblings and referring agencies, to be given upon completion of the study.

3.6.5: Causing No Harm

It is acknowledged that questions about personal loss can cause emotional pain. Research by Rosenblatt (1995) and Cook and Bosley (1995) which assess the stress experienced by participants in bereavement research concluded that participants perceive the opportunity to express their emotions and to discuss their losses as being helpful. Rosenblatt (1995) holds the opinion that "bereaved people gain enormously from talking with someone who takes their stories seriously and witnesses and acknowledges their pain" (p.144).

Potential harm to all participants was guarded against as follows:

1. All participants were told of their right to refuse to answer any question.
2. If the interview was too upsetting a participant could stop it altogether.
3. As the interviewer, I have both clinical interviewing skills and content knowledge in the area of grief and loss (Cook & Bosley, 1995).
4. Apart from giving emotional support I confined myself to the research and did not proselytize, advertise or advocate particular treatments (Parkes, 1995).

3.6.6: Maintaining the Boundary between Grief Research and Therapy

As my role was that of researcher not therapist, I did not engage in grief therapy. However, as noted by Rosenblatt (1995), even if a researcher is not engaged in therapeutic intervention the act of talking to participants about loss and grief necessitates that a researcher have clinical skills in listening, acknowledging, supporting and knowing when to back-off. The distinction is made here that while my request of the participants to talk of grief and loss may have provided a "therapeutic experience" it was not intended to provide grief therapy as my interactions were not focused on "growth and healing" (Rosenblatt, 1995, pp.149-151).

3.7: Information Management and Analysis

In using the qualitative approach of semi-structured interviewing wherein interviews were audio taped and transcribed, the analysis consisted of a systematic review of the transcripts to identify emergent categories and themes. As it was a priority that this study's conclusions emerged systematically from the transcripts, the general analytic approach of grounded theory method was applied (Denizen & Lincoln, 1994). Specifically, as each piece of information emerged from a transcript, it was compared to other pieces of information for its agreement or contradiction. This process of constant comparative analysis (Glaser & Strauss, 1967 as cited in Denizen & Lincoln, 1994) was used continuously throughout analysis with each piece of information that emerged. This process of comparing and then consolidating the information which emerged led to my understanding of the relationship between each piece of information within a category, between the overall categories and between this study's four themes.

Analysis began with my reading one transcript, being mindful of words and phrases which indicated experiences which were personally significant for the participant. Two more transcripts were then read and analyzed for information which agreed or contradicted the information from the first transcript. This analytic process was continued until all the transcripts were read. During this stage of analysis, I referred to the related literature to help me to either "confirm, elaborate, modify or reject" (Walker, 1985, pp.58-59) the connections which appeared to exist between the emergent pieces of information.

The transcripts were then re-read for the purpose of coding similar sections of information into categories. The content of each category was compared on the basis of being similar in topic. When it was established that categories were internally homogeneous they were then cut from the transcripts and placed together. The grounded theory method of constant comparative analysis and coding of homogenous pieces of information further allowed me to see how the categories related to each other thematically and how each theme was conceptually integrated into this study's conclusions.

The themes and categories are reported in the following chapter.

CHAPTER FOUR

Analyses of Information

Interviews from thirteen of the fourteen participants were audio taped and transcribed; L. chose not to be audio taped but did allow my note-taking during interviewing. Interviews from the seven participating family members were audio taped and transcribed.

4.1: Description of Sample

Information collected from the demographic information sheet is reported here. Parents and siblings completed only their personal information. Demographic information for thirteen of the fourteen participants was completed by a service provider. F. completed his own demographic information as he was not affiliated with a service provider.

4.1.1: Participants with Developmental Disabilities

Of the fourteen participants, six were women and eight were men. Their ages ranged from 24 years to 76 years old. Two (O. and E.) were in their twenties; four (C., D., M. and N.) were in their thirties; five (A., F., H., I. and P.) were in their forties; two (K. and L.) were in their fifties; and (B.) was in his seventies.

Formal diagnoses included: (1) mild mental retardation with epilepsy due to oxygen deficiency at birth; (2) undiagnosed developmental disability and epilepsy; (3) mental handicap, cause unknown; (4) moderate mental retardation; (5) profound mental disabilities; (6) undiagnosed mental disability (7) undiagnosed mental handicap and epilepsy; (8) three diagnoses of mild mental retardation; (9) two diagnoses of Down's Syndrome; and

(10) two diagnoses of mental retardation due to head injuries at the toddler stage of development, with one person born profoundly deaf and the other having developed epilepsy in connection with the head injury. Additional diagnosis included depression, suicidal tendencies, attention-deficit/hyperactivity, pedophilia and alcoholism.

Some diagnoses of mental incapacity were founded on an apparent lack of comprehension rather than on comprehensive testing. The diverse terminology suggests the subjective nature of the condition of developmental disability, indiscriminate labeling, and the lack of identifying strengths. Some participants appeared to have been labeled "retarded" on the grounds that they looked or acted as such at an early stage of development.

Diagnoses were made at birth, at pre-school age or at school-age. Developmental ages were reported for eleven participants. Five were reported to be developmentally between a 3 to 5 year level (B., D., K., N. and O.); P. was reported to function at a 3 year level; and C. was reported to function at a 9 year level. E. was reported to function at a "borderline" level which was clarified to mean about a 13 year level. L. was reported to function at an 11 year level. No developmental age was reported for A, H., F., I. or M. However, H. interacted during interviewing similarly to C. (9 year level). A. and M. interacted during interviewing similarly to those participants reported to be between a 3 to 5 year level. F. and I. appeared to function at an age-appropriate level.

Support persons were involved in interviewing to ensure meaningful dialogue for four participants. The verbal skills of the remaining ten participants were such that they could make themselves understood and they appeared to understand me. Some direct-care staff cautioned me that some participants' verbal skills belied their low comprehension and that they had the tendency to use words without necessarily understanding their meaning.

Five participants attended and graduated from a community high school's special education class (D., H., M., N. and O.). C. graduated from a segregated high school. A., E. and K. attended school for not more than three years; I. attended some community high school in an integrated class; B. had no formal education; P. attended a school for "challenged children"; F. attended a school for the deaf from the age of nine to fourteen; L. remained in the third grade in a rural school until the age of fourteen.

Seven of the participants were attending adult basic education classes. Only one of the seven (F.) appeared to be learning new skills. The attendance of the others appeared to be non-functional and to be a time-filler.

All fourteen participants reported a Canadian cultural background. Each reported that attending church was important; however, I. reported that he attended occasionally. Five reported to be Catholic; one Anglican; and one Protestant. Four belonged to Mennonite congregations. Both F. and L. strongly identified with their religions, Hebrew/Later Day Saints and Mennonite respectively. Apart from F., H. and L. it appeared that the participants attended church as a social function or as part of a weekly routine.

Residential living arrangements included one foster care arrangement; eight living in 24-hour supervised group homes; and three living in supported independent living programs. F. lived independently in an apartment in the community. I. was in transition from a group home to a twenty-five person boarding house.

Four participants had experienced the death of one person. Four had experienced the deaths of two people. Three had experienced the deaths of three people. C. had experienced the deaths of four people; B. the deaths of five people; and L. the deaths of six people. The deceased about whom the participants talked included parents, siblings, immediate relatives, a housemate, a boyfriend or girlfriend, or grandparents.

4.1.2: Demographics of Parents/Guardians and Siblings

The seven participating family members included two mothers, one father, three sisters and one set of foster parents. Each family member reported a long-standing and a current relationship with the related participant. The parents were aged 47 to 82. The three sisters were aged 33 to 59. Each family member reported a Canadian cultural background. All reported religious affiliation.

Family composition for four families ranged from three to seven children. Parental divorce was reported for two families. Re-marriage due to a spouse's death was reported in two families. For the seven participants without participating family members, two divorces were reported and the number of siblings was similar. These participants included family friends or cousins as siblings. Only P. did not know if she had any siblings. Two participants, C. and L., were adopted at three years old and three weeks old respectively.

4.1.3: Staff Persons

Direct-care staff from the four referring agencies arranged my meetings with the participants, provided demographic information and clarified some of the participants' statements. Four direct-care staff acted as support persons during interviewing. Most participant-staff relationships spanned between five to ten years; two participants had known their direct-care staff person for three years each; one participant had known her direct-care staff person for twelve years.

Some direct-care staff indicated their opinion that certain participants' were too "low" functioning to contribute to this study. They commented that this study would be too hard and that a participant's answers would be wrong. Inconsiderate statements by two staff made in front of two participants were: "No, no, that's not an accurate statement at all" and "I don't know if we can get to that with her".

All but three direct-care staff seemed to accept my explanation that it was not so important that a participant's story be "right" but that it is the personal meaning that social and life events have for a participant which was important. Findings which reflect contributions made by direct-care staff are reported as such. Staff persons did not sign consent forms and were not "participants" in this study although they were aware of my audio taping and intended use of the collected information.

Analysis of Interviews

Following the analysis process outlined in section 3.7, four themes were identified. The first theme reports on the participants' socialization histories and their lack of personal authority. The second reports on their authority figures' didactic communication with them which maintains their lack of authority. The third reports on the affects of their socialization histories and the didactic interactions on their personalities and self-concepts. The fourth reports on their death experiences and making sense of death. The themes presented here will reflect on the research questions and cited literature in the final chapter.

4.2: Negative Image

The words "Negative Image" are used as this theme's title to reflect the unprocessed state of the participants' socialization experiences. The analysis of their social and life experiences indicated that they had no opportunities to direct the events of their lives or to raise their concerns and questions in relation to these events. The word "negative" is not a critique of the participants' histories, rather it indicates the participants' lack of clarity regarding their life circumstances. Like the negative from a photograph, clarity will be gained through processing. However, as will be reported in the next theme, their communication with others does not offer them opportunities to process their questions and concerns about their circumstances, it is didactic if it exists at all.

4.2.1: Experiences of Parental and Family Rejection

Home for many of the participants was not the "supportive holding environment" which Applegate and Barol (1989) suggest is optimal for children's development. Nine of the participants reported to have experienced rejection from their parents, siblings and extended family. None of the participants talked to their families about this rejection.

C. stated that she knows her parents sent her to an institution because "(they) did not want me". The fathers of B., F. and N. were reported to have blatantly rejected them. B. vehemently spoke of his father as the one responsible for his institutionalization and said of him: "Hate my Dad. Dad didn't like and I don't like (him). He was a creep". N.'s sister, Mrs. W., recalled an incident where N. noticed his father on a city street and he ran towards him and his father responded by walking in the opposite direction causing N. to stand "looking lost". A similar incident to N.'s was reported by P.'s direct-care staff to have happened between her and her mother. F. reported the most anger and sadness regarding his father. He said that his father did not accept his "handicap" and accused him of pretending to be disabled F. stated the following:

> "All my life I grow up, my Dad never loved me, never put his arms around me and said I love you son. He wanted me to go into (an institution)."

Similarly to F., N.'s father also rejected his disability. N.'s sister recalled that their father said: "That's not my kid". N.'s sister also said that their mother would force him to talk properly. E. used the words "puzzle" and "brickwall" as he talked about his relationship with his mother. Due to his pedophilia, his family has shunned him. M.'s mother repeatedly stated that she treated M. "just the same" as her other children. Rather than accept M.'s disability, her repetitiveness on this matter indicated she did not want to acknowledge that he was different.

Due to prolonged sexual abuse by her father and brother, O. stated that she could not "trust" them and that when she does go home her brothers say to her: "You don't live here anymore, go, out the door!"

N.'s sister reported that she and her siblings except for one rejected and ridiculed N. when he was a child. F. reported his brothers rejected him and "they forgot who I was".

Relationships with extended family were non-existent for all except M. A.'s mother said that A. regards the relatives that ignore her as "used-to-be's and has-beens". N.'s sister said that: "I've got this big family and nobody ever sees him". M.'s mother feared he would be excluded from family events after her death as he now visits with the family through her. Since her mother's death, this fate had befell D.

4.2.2: Experiences of Infantilization

All of the participants experienced varying degrees of infantilization wherein they were treated as if they needed protection and assistance in decision-making and in daily-living. Most of the participants appeared to accept their infantilization. H., I. and L. who were aged 41, 42 and 52 respectively were so accustomed to their parents meeting all of their needs each wanted to still be living with their parent(s) had they not been deceased. Having to be "watched" by others was reported by or of participants E., L., O. and P.

Only two participants referred to markers of their maturity which included graduating from high school and turning twenty-one and being allowed to drink beer. Eight participants did not know their ages or the year of their birth. Concerning her age O. stated: "I know I'm not two any more because I graduated". K. thought he was twenty when he actually is fifty. D., who was thirty-years-old, insisted she was a "little girl". D.'s confusion concerning her maturity was understandable when I met her sister, Mrs. X., who referred to D. as: "She's a wonderful little girl and a wonderful lady, little woman".

Five of the participants, A., D., H., K. and N. were said by family members and direct-care staff to be called "baby" and treated as such by their parents without their objection. The mothers of D., K. and N. were said by direct-care staff and one family member to react to them out of a sense of guilt. K.'s mother is said to dote on him and to almost carry him out the door when she takes him out. D.'s sister said that their mother did so many things for D. that she did not even need to talk when she was with her mother and that for weeks after visiting her mother she would not talk at her group home.

F. was the only participant to harbour anger towards his mother for her infantilization of him. He stated:

> "I lived with my Mom all of my life. I never had a chance to live on my own. She didn't want to let me go because I was the son that was born deaf. 'Who was going to look after me?' "

M. serves as an example of how some of the participants' requests to be seen as mature were not taken seriously. M. wanted to leave his parents' home after he saw his younger brother leave home for college. Of his request to move out, his mother stated she said to him:

> "'Oh, someday you will.' And then of course we'd joke about it as say, 'You can't live with a girl!' We just joked to him and ribbed him about it."

Of those participants who spoke of sex, none had ever been involved in a sexual relationship. Relationships with boyfriends and girlfriends were platonic and it was stated by family members and direct-care staff that related participants would "not know what to do" concerning sex. F. said that he was never taught about sex and that he learned by attending a sexual education course at the age of 37.

4.2.3: Experiences of Social Disruption

Seven of the participants' disabilities placed them outside of the family home during their childhood's. This first experience of social disruption appeared for these seven to represent the "hub" (Kauffman, 1994) of all of their circumstantial losses. All of the participants except for F. lacked control over when they left their parents' home, where they moved to and live now, who they live with and when they will next move. F.'s experience was different in that he wanted to leave his mother whom he thought was too controlling of him. It took until her death for him to gained his "freedom" from her and her guilt.

When the participants left their family homes they all entered socially segregated environments including institutions, groups home and foster placements. None has ever returned to a non-segregated social environment. Many experienced multiple moves and have wished that they could have been brought up like a "normal human being" as C. stated. Although F. lives independently in the community, he is isolated in his apartment and lacks the social skills and the confidence to circulate in a non-handicapped social environment.

The participants' sense of being unattached to their families was well stated by A.'s mother. She said:

> "A. never considered my house her home. We were more or less strangers to her, even if we didn't want to be like that. She felt that when she went back to the hospital, she was back home."

A. stated her view of leaving her mother's home as, "I tried to live with (my mother) a long time ago" and that now she just tries "to stick to her" whenever she can visit her now. This statement is representative of many of the participants who have relationships with their parents or siblings. A. also recalled how she would run away from an institution to return to her mother's house which was nearby.

For those participants who left home during their childhood's and who actually received an explanation about why they were leaving, the most common explanations they stated were that a parent could not cope with their care taking demands; they left when a parent told them to; or they left because they were told they would be "happy" living at their new residence. Only two others had different explanations: M. asked to leave home at 22 to be like his younger brother who was leaving for college and O. left her home due to her sexual abuse.

The four participants who spoke of living in an institution spoke about poor living conditions including seeing rats, poorly cooked food and few or no visits from their families. The repercussions of the participants' first social disruption, their subsequent moves and the uncertainty of why they could not have stayed living at home with their parents and siblings included for some participants feeling abandoned. some feeling that no one wanted them and some worried about and clung to their parents when they visited them. P. was the only participant to speak about how little control she had over leaving her parents' home and how she was not the one to disrupt their relationship. Her statement to this effect sounds nonsensical but it does emphasize their culpability:

> "I did not move out...they (her parents) have to see me here (her group home)".

For those who left their parents' homes after their parents died, the social disruption appeared harder to bear. L.'s sister's characterization of L. being traumatized by the changes his parents' deaths brought were representative of the depth of loss the other participants who had lived with their parents until their deaths experienced. She stated:

> "He had a nervous breakdown. He had the loss of his parents, his home, the home community, a church loss, the loss of (the family businesses), and he had the loss of the animals (his job)."

The sadness and lack of control many of the participants associated with the leaving of their familial homes and the social disruption created by many more additional moves appeared to be factors in the participants not wanting to change their present residences. Only I. sought to leave his residence. He stated that he only lived in a group home because it was his "dad's idea" and since his father's death he had planned to move from his group home so as to end his association with the "mentally handicapped".

4.2.4: Experiences of Social Segregation

Regardless at what age the participants experienced their first social disruption which inevitably moved them to segregated residential living, all of the participants were segregated from the non-developmentally disabled community. Besides living in segregated housing, most were segregated in their schooling, jobs and leisure activities. For all except F. their daily activities were not of their choosing and did not appear to have personal meaning as they commonly stated that they follow staff's directions. Most appeared to live according to their schedules of activities which were prepared by their care takers. Mr. J. described his daughter's life as if it were a treadmill: "H. lives in two week periods. Because she comes home every second week".

Eight of the participants worked only in their residential agency's workshop. None had a good opinion of their workshops and the words "lousy" and "boring" were used by three to describe their work there. Their workshop employment included washing and drying dishes, sweeping the floor, food preparation, and assembling headphones. Only F., I., L. and M. had jobs in the community which were the same as would be occupied by people without developmental disabilities: factory worker, worker in a seed supply store, lawn maintenance and a grocery bagger. The benefits of working for all appeared to be the money they earned, two mentioned that their jobs gave them something to talk to their families about, one stated that his job made them feel "important" and another said that without a job he would feel like a "loser".

None who worked in a workshop had chosen their work sites and for the four participants working in the community their jobs were made available to them on the basis of their disability. While the work of most appeared to be make-work, only two said that they wanted to change their jobs. O. said that she wanted to be a secretary or a waitress but she also stated, in words which appeared to be of her staff, that these "jobs would be too hard for me". A. wanted to be a baby-sitter. Neither A.'s or O.'s direct-care staff appeared to have made an effort to address their requests.

Those who attended segregated schools spoke about their education being substandard. F. stated: "I wanted to learn a lot, but the handicap school can only go so far". M.'s mother, Mrs. V. stated that M. was removed from a segregated school and placed in an integrated high school because he was:

> "...coming home and acting like a baby at times instead of an adult and doing things that weren't the way they had been. Instead of acting like a normal adult he was beginning to act and talk like mentally handicapped. ..we wanted him to progress rather than regress. So we took him out of there."

L. attended a rural school until the age of fourteen. His teacher segregated him from his peers by keeping him in the third grade every year. L.'s sister's, Mrs. R., said that the teacher would place him into "a bigger and bigger desk, but he always sat on the primary side of the room". Mrs. R. said that her brother experienced this segregation as rejection.

The participants' most common leisure activity was watching television usually in their bedrooms alone or with their room mates. Two participated in activities with the

Special Olympics. Most attended nightly activities such as swimming or shopping as part of a group consisting of the other residents from their group homes. Church was attended as a social activity or as a part of their weekly routine; only F., H. and L. attended for personal, religious reasons. Most participants did not have the opportunity to go on a vacation, although many had ideas of places they would like to visit. B. had his first vacation at the age of 74; F stated: "All my life I've been in the house. After my Mom died I took off to Salt Lake. I'd been planning for thirteen years to see this place"; and P. whispered to me that her wish is to be allowed to go to her parents' cottage.

4.2.5: Experiences of Social Rejection and Labeling

Experiences of social rejection and labeling were reported by or of each participant. While most incidents of teasing and name-calling occurred during their first years at school and in their childhood's, some still experienced name-calling, staring and social distancing from others in the community. The most common name the participants were called was "retarded." Of the participants who made reference to the word "retarded" none identified with this term, in fact all participants attributed their difficulties to less stigmatizing conditions. Of those who referred to this term most said they got mad at others for calling them this and that this word made them feel bad about themselves.

The alternative conditions the participants attributed their disabilities to included being: slow; hyperactive; alcoholic, hearing impaired, having seizures and needing help with dressing, making their beds or cooking. P. made the statement that: "I'm not slow. But the teachers are slow". C. was the only one to say that she was "brain damaged" and that she was not mentally retarded but mentally challenged because she had challenged herself through the Special Olympics. Six people stated that they had never been referred to by a name suggesting they were mentally impaired.

Most of the participants had never discussed their disability with their parents. M.'s mother said she did not discuss with M. his childhood incidents of being teased or, one time, being burned on his lip with a cigarette by children. She stated:

> "We never dwelled on anything negative because it does not help much. So you just sort of overlook it and just carry on like just the same."

H.'s father, Mr. J., said that he had talked to his now 42 year old daughter when she was between 12 and 15 and told her she had epilepsy. He stated: "I guess she had enough faith in me to say, 'Well, I don't have to question it any further.' " C. was the only participant to say that her mother explained to her that she is "just a little retarded". She credited her mother with helping her to accept her condition of being brain damaged.

Although most did not have the opportunity to asks questions about their disabilities, they all appeared to be aware that it was better not to be considered disabled. Five of the participants, E., F., I., L. and M. distanced themselves from being identified as "retarded" to the extent of not wanting to associate with people with developmental disabilities except for those at their residences or workshops. I. stated he does not "hang around" with people with disabilities because "...you can't communicate with (them), you try but you're not getting nowhere, you feel left out". During interviewing, one participant, M., gave his house mate orders and referred to him as needing a lot of help, appearing to demonstrate that he was more capable than his house mate.

Seven participants also engaged in impression management; that is, referring to their personal possessions, haircuts or clothing as a means to distract from their disabilities. The participants' behaviours of not accepting their disabilities as a part of their personhood and distancing themselves from labels and from others whose appearance or behaviours indicated cognitive impairment, suggested a loss of inner self-worth. That each of the participants was uncomfortable with a "retarded" identity to the extent of shunning this part of his or her personhood, demonstrated that they had concerns about their social acceptance. That their parents did not talk to them about their disabilities may have encouraged them to likewise engage in the coping strategy of not accepting their disabilities.

4.2.6: Experience with Social Relationships

For many the on-going experience of social disruption in combination with living in segregated social environments contributed to their having limited social relationships. Those who had relationships had an isolated relationship with one family member. None of the participants had friends outside of the people with developmental disabilities that lived at their residences or worked at their workshops. Two participants, F. and L., turned to their church congregations to find, as F. stated, "people who like me".

Seven of the participants regarded their direct-care staff as either their "friend" or "buddy". P. referred to her direct-care staff as "friends" nineteen times during interviewing and repeatedly said she says to staff, "Excuse me, can I just have you for one second to talk to you?" B. referred to his support person as his wife. O. referred to a staff person as the only person who understood how she felt "emotionally on the inside". Generally, the participants appeared to be dependent upon their direct-care staff to fulfill their instrumental and emotional needs. Family members for D., M., and N. thought their relationships with specific direct-care staff were critical to their day-to-day functioning and these family members said that the residential agencies were like "family" for their related participant.

Five of the participants had contact with a family member and they appeared to place a heavy reliance on these relationships. L.'s sister felt he would have a nervous breakdown if his siblings died before him; Mrs. V.'s concerns of M. were that he always believed he would have his family around him and she sensed that after her death he would no longer be included in his siblings' lives; H.'s direct-care staff stated that she "lives for" her father and as her father said, H.'s life revolves around her visits with him; D.'s sister similarly said of D. that their mother "was her life"; and A.'s mother said that she knows A. "depends on me for love" and A. said that she misses her mother so much in between their visits that she dreams about her and she waits for her mother to call and visits "whenever my mother has a chance to be able to let me".

The participants' anxiety about maintaining their relationships with a family member resulted in certain behaviours by which they tried to position themselves close to their family member. H.'s father said that she will often call him and "she's asking about the dog, the birds, everything else. She keeps you on the phone and tries to keep a long conversation going". N.'s sister said that he often calls and cries on the phone that he wants to go to her home. She also said that N. has become violent with her when he fears losing her attention such as when she was pregnant and he kicked her in the stomach as he was concerned about losing the attention of "his people" (his sister and her husband) to her baby.

M. stated that as he lives close to his mother he goes to "check her house". L.'s sister said that he calls on the phone and says "Keep me in mind" and that he also leaves similar messages in her mailbox.

Anger at a lack of control over having friendships was stated by F., he called this one of his "trials" in life. L.'s and N.' sisters said that their brothers' lack of having friends is a pattern which has existed since their childhood's. They stated that other children would mature beyond their brothers' age levels and then they would be left behind. Desertion by a friend was mentioned by or of three participants. L.'s sister stated that when a long-time girlfriend stopped her relationship with L. that he stated "Why didn't she like me?", became suicidal and required long-term psychiatric hospitalization.

Most of the participants talked of wanting to be married. Five participants did have a girlfriend or boyfriend which they knew from their residential agency or workshop but only one regarded his now deceased girlfriend as someone he would have married. The others, who were all women, appeared to regard their boyfriends as replacements for family members or as possessions they were supposed to have. While they each talked of marriage none said they would marry their boyfriends. Only F. spoke of how a sexual relationship was less important to him then finding a woman who would accept his disability.

Most of the participants appeared to be lonely; only C., F., and L. stated this. It was said of E., L. and N. that they know many people but they are not close to anyone. N.'s sister made a statement about her brother's neediness for relationships which appeared to be true of many of the participants. She stated:

> "It doesn't matter how much bad they do, or how much rejection they deal out, he's there as long as (he can be). He only gets a little piece at a time, so he relishes those pieces. So the bad that comes with it, he will flush the bad."

Another summary statement about the state of most of the participants' social relationships was made by L.'s brother-in-law. He stated:

> "He invests a lot of time and energy (in relationships). He wants to connect with people. I interpret all of the people, anyone he has ever met, is a loss for him. It's different for me, I knew that person, but not a close friend, but that doesn't make much difference to L."

Due to their lack of control over attaining and maintaining relationships, some of the participants resorted to social substitutes. All but four had family photographs which they often looked through. P. was the only participant to not have any photographs of family or friends and referred to a magazine as her photo album and kept a frame with its original photographs as she had no others to replace them.

Social strategies to gain friends which were employed included: two retained in address books the names and phone numbers of every person whom they met; two initiated telephone calls; one walked up to strangers and introduced himself; one stood by the street and waved to passing cars; and three male participants gravitated towards children for friendship. Three participants appeared to solve their problem of having unstable and fleeting relationships by forming relationships with inanimate objects; one his parents' furniture, one her television and one his twenty-year old radio.

None of the participants had a conclusion for why their relationships dissolved or failed to appear. Only three participants spoke of adding people to their lives; two gained step-parents and one gained nephews and nieces after searching for his sister who, unfortunately, was deceased by the time he located her. Most of the participants appeared to be monitoring their relationships for signs of life, however, one participant, L. carried this to an extreme by scanning the obituaries daily to see if anyone he knew had died.

4.2.7: Experiences of Failure and Frustration

Most of the participants did not speak of having experiences of failure. Only two participants gave specific examples of things they cannot do; M. said that he has tried to drive a golf cart and knows that driving a car is something he "can't handle" and O. said that she always gets frustrated when she has to try and figure out where to replace dishes in her residence's kitchen and that incidents similar to this can make her "feel like a mistake". Rather than directly address experiences of failure, participants E. and L. stated that not even God, as F. stated, or a preacher, as L. stated, "expects you to be perfect". Of the participants with whom the topic of failure came up, most were similar to C. and L. who referred me to a Special Olympics' medal and a certificate of achievement, respectively, as hard evidence of their success.

Most participants appeared not to have opportunities to have responsibility and, in general, lacked opportunities to engage in purposeful activities. L.'s sister stated that she has heard her brother often state: "It's good not to have responsibility". N.'s sister made a statement which appeared to apply to more participants than just her brother concerning his not talking about having failures: "He was more protected from failing than having a chance to". M.'s mother made a similar comment concerning M.'s lack of dwelling on his failures when she stated that she had protected him from activities she thought he may be hurt by or be frustrated with.

Family members and direct-care staff stated that they did notice that related participants would get frustrated when attempting certain tasks but that they did not appear to get angry at themselves rather they directed their anger at others. Seven participants

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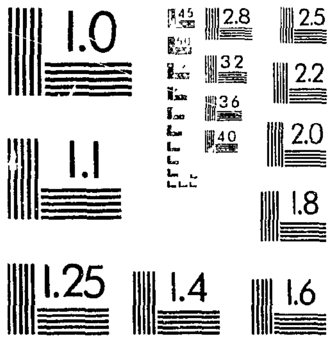

PRECISION^{SM} RESOLUTION TARGETS

were said to project what appeared to be self-critical comments onto others. A common example was that rather than say he or she was "stupid" a participant would say another person at his or her residence or workshop was "stupid" and the cause of him or her not being able to accomplish a task.

Given their infantilization, lack of authority over many areas of their day-to-day lives and social relationships, and lack of opportunities to have responsibility many of the participants appeared to re-frame any instance of their associating with another as their "helping" the other person. This will be reported on in the analysis of the participants' self-concept characteristics.

4.2.8: Seeking Explanations

Analysis of the participants' socialization histories identified a general lack of information and understanding about their personal circumstances. Common statements were that they work where they do, or live where they do, because they were told to do so. Only a few made statements to me which indicated that they do have questions about their life circumstances. The possible reason for their general lack of questioning others and raising personal concerns was identified in the analysis of their parents' communication style with them which will be reported in the following theme.

Two participants raised the general question of "Why?" in relation to their interactions with others. The family members for two other participants identified examples of their seeking explanations.

F. was by far the participant who most verbalized his quest for explanations and his desire for others to ask him about his thoughts and feelings. He said:

> "They never come and asked me what I thought...never asked. I always wanted to ask the question, they never asked and that just hits me. I wanted to say something. I couldn't get it out of (my) mouth. That's all I got in my face, never asked me why. I didn't know what was going on. I wouldn't say I was a happy person. In my opinion, I like the people to sit down, close their mouths and start listening. These handicap people are frustrated."

F. also stated that he has asked himself "why" regarding his trials in life as a "handicapped" person. He stated: "I don't know why, out of the blue, I thought like, what am I doing...I killed myself laughing because I don't know why".

O. stated that she, "Just can't figure out why" she has been abused by her father and brother and why her family, save her mother, acts as if she should stay away from the family. It appeared from O.'s statements that she struggled with trying to understand why she has had to leave home and is rejected by her family when it was her who was victimized. Although her mother has advised her to just "forget about" her abuse, O. said that she is preoccupied with the question of "Why did it happen to me?"

Mrs. W. spoke of her brother, N.'s, penchant for taking things apart. She identified that in a figurative sense, maybe N. is showing through his behaviour, that he is seeking to understand how and why things work.

Mrs. R. spoke of L. raising the question "Why?" when he is in deepest despair; when it appears to him that life is not worth living. She provided two examples of his seeking explanations as when a girlfriend deserted him and when his father died and he was asked by the family to vacate the house that they had shared.

4.3: Didactic Communication

The analysis of the information from the participating parents identified that they communicated with their related participant in a style that suggested they spoke at them rather then with them. Along with the participants' socialization histories of infantilization which appeared to inhibit their asking questions of their authority figures, a history of didactic communication appears to have contributed to the participants being conditioned not to ask questions about their past and present social and life events.

There was not one example of communication from a family member which identified a style other than didactic discourse. Analysis revealed that parents' communication resulted in a didactic manner of speaking to their related participant for one or more of three specific reasons: they did not think they had any questions; they did not want to create anxiety in them and therefore did not discuss certain events; and the most common reason for not asking for their opinions, concerns or questions appeared to be the parents', as well as siblings' confidence that their related participant was happy and content in his or her lifestyle.

The following statements made by the parents of A., H. and M. identify that they did not think their adult children had questions they wanted to ask.

A.'s mother, Mrs. G., stated:

> "If you say (to A.) you're going to go here or you're going to go there, she does it and says nothing. Doesn't even ask why. She never resisted."
>
> "No, there's no questions. You say, 'A., do it' or 'A. you should do it."

Mrs. G. also provided an example of how A. does not think to raise her own questions because she is led to believe she is actually making her own decisions. Mrs. G. stated:

> "If there's a decision to be made, then of course, (A.'s staff) phones me and tells me what it's all about...then I say we'll talk it over. I know (the staff's) views, so I talk A. into thinking that (the staff's) views are the best views. I always tell her I think it's good for her... I don't say well that's (the staff's) views, I say, 'Well, I think it is (for the best), don't you?' You can talk around her you know."

Mrs. G. also stated an example of how she has groomed A. not to ask questions of others. She stated: "I've always (said) behave yourself and listen to the nurses and the girls and you'll be happy".

H.'s father, Mr. J, stated that after telling his daughter that she had epilepsy that it appeared to him as if she understood and was satisfied with his explanation. He stated: "I guess she had enough faith in me to say, 'Well, I don't have to question it any further.' " What Mr. J. does not say in this statement or in any of his others was that he specifically asked H. if she had questions or concerns regarding his explanations.

Mr. J. provides another example of his assuming that H. does not have any questions. When speaking about H.'s inclusion in family gatherings Mr. J. stated: "There was no real reason for her to question, 'Why am I being left out?' No, she never brought it forward if she did think of it."

M.'s mother said that M. does not ask questions that: "M. is very easy that way. He will do whatever I want to do and whatever I'm doing he'll just go right along with it".

Two additional findings of participants not being considered to have questions to ask were identified in statements by N.'s sister, Mrs. W., and D.'s sister, Mrs. X..

Mrs. W. indicated that her mother did not give N. credit for being able to communicate at all, let alone to have a question. She stated: "She talks as if he's not here. If he were here sitting between you and I, she'd just say it to me". Mrs. W. also added that because N. has always been excluded from conversations and because her family has many "family secrets" she herself has "never discussed any key issues with N".

D.'s sister stated the D. and her mother had a "silent communication" where D. did not "bother" to talk to her as whatever her mother did or said was accepted by D.

The following statements by the parents of A., H. and M. identify that they did not give their adult children information or discuss certain topics that their adult children already had an awareness about as they did not want to create anxiety in them.

Mrs. A. stated that when A.'s father was dying in a hospital that she did not allow A. to see him and that she did not tell her of his death, or her brother's death, until months after the events. She stated:

> "(I) never took her because I didn't know how she would react. I was a little bit concerned for A., if she should see him in that condition."
>
> "Quite a while after (A.'s father's death)...I said, 'Did you know that (your father) is gone?' That's when we told her about her brother too. We didn't let her know exactly when he died, we waited for a while to break it to her at sometime when she wasn't excited about anything."

H.'s father did not talk to his daughter about his illnesses although she had stated to him that she worries about his health. He stated:

> "I had a (heart) operation ...maybe it was wrong, maybe it was dead wrong, but I didn't want to put H. really through it. When I say hid it from her, we didn't talk about it. She knew I was in the hospital, but she didn't know really why..."

M.'s mother Mrs.V. said that she does not talk to M. about things which she thinks would upset him including his father's death. The following statements are Mrs. V.'s..

> "I think we try to keep from him the sad things that have happened and maybe that's not the right thing to do. ...we know he does get very sad about things. There's been a lot of things we keep from him."
>
> "I don't know what he was thinking at the time (of his father's death)...We've really never talked about it. I know that he does a lot of watching of me when we are driving and he knows we are going to the cemetery. I can see him glancing over at me every few minutes."

The third reason why some participants were not asked for their questions or concerns was identified as their parents' certainty that they were happy with their lifestyles and would not have any complaints. It appeared from both the parents' and siblings' statements that they cajoled their related participant into thinking that their lives were fulfilling and in the process also deluded themselves about the richness of their related participants' lifestyle. It was identified in the analysis of the following statements that the parents and siblings do not mention the related participant's deficits or restrictions as affecting their lifestyles. Also activities which the parents and siblings mentioned as signs of happiness were not mentioned by the participants themselves.

A.'s mother stated that she thought A. liked to live her life on a "slow cycle". While speaking about the quality of A.'s lifestyle Mrs. G. stated:

> "I always tease her and tell her that she has a better life than I do because I (tell her) it's more interesting. I said you get to go to dances and she went to the ice capades...I keep telling her that I would love to do things like that."

Mr. J. said he thought H. was happy with her lifestyle as she liked her room mate and she liked to tell him about her job. He stated that he jokes with her about her activities. He stated that "she has opportunities to go to dances and so on. Why I almost have to make an appointment with her to find her home".

Mrs. V. stated that: "I think M. is just one person who accepts life as it is. He's happy with what he does. He's happy with his jobs. He's just an overall happy person...He's built up quite a life and he likes it, he's happy..."

D.'s sister stated that she thought D. "accepted what her life is. She is quite content...She's always been a happy kind of person. I think she is accepting...she does her usual stuff she likes doing and we take her places".

D.'s support person also made a statement concerning D.'s contentment. She stated: "She's established, she's financially okay, she's getting an education, she's got a job, she's got a home, she's got friends, she's got skills, and she's okay".

The findings from the analysis of the parents' manner of communicating indicate that a history of infantilization paired with a history of didactic discourse may have been operating together to stymie the participants' development of personal authority as reported in the first theme. These dual histories may also serve as an obstacle to their making sense of their personal life circumstances as they are not viewed as people in need of the opportunity to ask or to be asked about their life circumstances.

4.4: Personality and Self-Concept Characteristics

The reported information reflecting the participants' apparent socialization histories and histories of didactic communication complements the analysis of their personality and self-concept characteristics. These characteristics were identified as representative of their experiences of social disruption, social deprivation, social segregation and infantilization. Also identified was that their personality and self-concepts appeared to have an underlying structure of unresolved circumstantial losses including abandonment, rejection, stigma and dependency issues which served to maintain their personalities and self-concepts in a defended and vulnerable state as discussed by Edgerton (1967, cited in Wilson, 1970).

The four identified personality characteristics which are significant for the unprocessed issues attached to them include: seeking social attachments; passing and denial; and dependency associated with acquiescence. The three identified self-concept characteristics include variables of intimacy, success and self-determination and are significant for the unprocessed interpersonal issues attached to them.

4.4.1: Seeking Social Attachments

Many of the participants' experiences of social disruption and social deprivation appeared to leave them with unprocessed issues of rejection and desertion which were displayed in behaviours of trying to establish or maintain relationships with others. L. displayed a need to stoke his relationship with his sister by sending her messages by phone and mail for her to remember him. E. displayed his need to be remembered by phoning others to let them know he was "thinking about them". Most who lived in group homes were said by their direct-care staff to routinely ask when staff will return for their next shift. N.'s sister's statement that N. needs to "regenerate" his bond with those he counts on for acceptance and approval appeared to be representative of many of the participants.

4.4.2: Passing and Denial

The participants' experiences of stigma and social rejection appeared to cause each to have unprocessed concerns about their social acceptance. Each participant engaged in some type of protective strategy to cope with their disabilities. All of the participants attributed their cognitive disabilities to less stigmatizing conditions. E., I., L., M. and N. each presented themselves as better than lower functioning people at their residences or work sites. A., H., L., N. and M. engaged in a strategy of impression management to draw attention from their disabilities to their possessions, clothing or haircuts. Five of the participants also avoided associating with people with disabilities.

4.4.3: Dependency and Acquiescence

The participants' experiences of infantilization and social deprivation appeared to cause each to have unprocessed concerns about isolation and compliance which were expressed by specific social behaviours. For those participants with family members present in their lives most were dependent on them to the extent, as L.'s sister's phrased it, of being their "shadow(s)". Many of the participants were dependent on staff to act as substitutes for relationships with family and friends. While most of the participants accepted without question the directions or explanations given to them by authority figures, seven participants appeared to use an automatic acquiescent response as a strategy to either hide ignorance or gain social approval.

4.4.4: Lack of Intimacy

The participants' histories of being placed in infantilized dependent positions relative to others in their social environments appeared to create in many of them unprocessed concerns about receiving love and about being able to give their love and care-taking to others. For all participants their intimacy needs, especially their need to give love, appeared to be frustrated and unfulfilled as discussed by Bogdan and Taylor (1982). Many of the participants' unsatisfied desires to give love and happiness to another was expressed by them through a favourite song. The use of song lyrics to convey their intimacy needs was arrived at by a participant playing for me his favourite song which spoke of the desire to receive real, not imitation, love. Seven of the participants reported a favourite song which expressed their desire to give others their love through marriage and intimate relationships. Three participants reported favourite movies which similarly had a theme of love, marriage and shared living.

4.4.5: Lack of Success

The participants' common social experiences of being protected from making an effort and, for most, having no actual responsibilities relative in importance to non-developmentally disabled people appeared to create in many the unprocessed issues of personal inadequacy and for at least one, I., shame. The issue of concern appeared to be the lack of opportunities to be successful or to have responsibility and appearing incapable rather than an issue of having failures. Many of the participants defended their competency and abilities by re-framing their interactions with others to where they were helping others. Nine of the participants stated that rather than "work" at their work sites they "help" or "help out" there; two participants spoke about how they had to "help" a parent grieve.

4.4.6: Lack of Self-Determination

The participants' combined social experiences of infantilization, social disruption and history of didactic communication appeared to have muted their need for autonomy and caused many to have unprocessed concerns about self-confidence. The participants commonly made statements which indicated their lack of opportunity to make choices and decisions. Repeated statements made by A., P. and O. were representative of many of the participants. A. stated: "It would be up to staff" and "if it's okay with staff"; P. stated twelve times: "But what can I do?" and also "Anything staff tells me to do I go do it"; and O. stated: "I'll have to wait and see what staff wants us to do" and "The staff decided..." Making personal decisions was so foreign for one participant that he would sit for hours waiting for a staff person to come by and give him directions.

F. and I. were the only two participants to be angry at their lack of freedom to make choices. Although wanting more personal freedom, F. stated that he was concerned about making mistakes and wanted to make the "right" decisions in his life in order to disprove the names of "stupid" and "dummy" he had been called. I., for the sole purpose of disproving his dependency and his label of "mentally handicapped," decided to leave his residential agency for a boarding house. The participants' lack of self-determination appeared related to their almost unanimous agreement in not wanting to change their daily activities.

The findings from the analysis of the participants' personality and self-concept characteristics indicate the effects of their lack of opportunity to process their social and life experiences. The unprocessed state of their socialization histories appeared to yield circumstantial losses which shape and maintain defended and vulnerable personalities and self-concepts.

4.5: A Montage: Making Sense of Death

The general absence of processing accorded to and by participants of their social and life experiences becomes more poignant in the analysis of information reflecting directly on their death related issues.

The word "montage" is used as this theme's title to reflect the composite picture arising from the analysis of the participants' grief experiences and the sense-making of death. While the social and life experiences of this study's fourteen participants are different, they present a picture — a montage of social experiences and grief experiences the significance of which have been minimized by succinct explanations.

This theme's three categories address the participants' apparent reactive grief; that is, an outward orientation concerning the loss of the relationship; their explanations of death; and the participants' lack of existential grief; that is, an inward orientation concerning the question of why death happens which will be addressed in juxtaposition to the concept of causality.

4.5.1: Reactive Grief

In grieving the ending of their relationships with significant others, all of the participants expressed varying degrees of affective responses. The two most common reactions were reported as crying and sadness. P. expressed her sadness as being "an ache inside of you (that) comes out". A., D. and L. were reported to have "very little reaction" to the deaths of their loved ones. Mrs. R. reported that her brother L. only cried at his mother's funeral and then a few months later indicated he did not want to be reminded of his mother's death by saying: "I think we've talked about this enough". L.'s sister said that he had been traumatized by his mother's physical appearance before her death and to have said: "Why can't she die." D.'s direct-care staff was concerned that she would deny her mother's death as she had done a friend's death and this staff, in her own words, "forced" D. to engage in the staff's seemingly dictated process of grief work. She stated:

> "I worked really hard for a long time...She's gone through the whole process. It's been forced on her, a lot of it....she's been angry, she's been sad, she's been confused...I went so far as to take her back to the hospital the night her mom passed away..."

K. and P. both substantiated the anger they felt towards their house mate for dying by saying that: "he died on me," "he died too quick" and "he left me". Guilt was expressed by two participants; N. who was said to be handling the gun which fired and killed his sister and E. whose sexual abuse of his sister caused her to move to another city where she subsequently was killed in a car accident. L. was suicidal after his father died and was hospitalized for one year following his death. F. displayed the most unexpected affective response: happiness. He referred to his mother's death as a burden removed from him. He stated:

> "I don't have to worry about her going through pain. I don't have to worry about whether she is angry on account I didn't (do) the right things. It's a burden off you."

Two participants referred to the length of their grief. K. expressed his sadness and anger for about two months and I. said he grieved his parents deaths for one year. D. was the only participant to display sadness and crying during interviewing. Each time we met she sat with her life event document in her lap and pointed to where her mother's death was written and cried.

Several participants made reference to maintaining a connection with the deceased. B. referred to his girlfriend as "a star looking down on me". C. said that her parents return to her in a "spiritual way" and that she tells God to "make sure to keep my parents safe". D. asks her direct-care staff about the possibility of her mother returning for Christmas or for a walk in the park. I. spoke about catching himself buying a Christmas present for his deceased mother about which he stated: "OOPS, caught myself, force of habit". H. gave a poignant description of her wish to be rejoined with her mother and brother. She said:

> "...they're up with God and Jesus. I wish they came back from God and Jesus because I feel very sad. I wish they would come back to see me. Like tomorrow, I'm going home to see my dad."

M.'s effort to maintain his relationship with his father included referring to his father in the present tense. His direct-care staff and mother were aware that he did this but had no explanation for its occurrence. It appeared as if M.'s referring to his father in the present tense was related to his mother's coping style of accepting things as they happen and carrying on as if things were normal. Just as his mother has not talked about his disability with him or his father's death and gives the impression that she dismisses his disability, M. may be similarly dismissing the reality that his father is no longer living and death need not change their relationship.

Most also maintained relationships with the deceased through their collections of family photographs and video cassettes and by retaining and displaying personal effects such as furniture and jewelry.

Some participants stated that an important part of their grieving was to be able to see their loved ones before they died. B., C., D., H. and M. all wanted to visit their loved ones in the hospital. I. said that he had missed by a few minutes his mother's death but that he was prepared for his father's death and that "he died in my arms". E.'s guilt caused him to wish that he could have been with his sister at her death. He said:

> "..it was my fault. I did not have a chance to say good-bye to her. I didn't even have a chance to tell her that I loved her. I just wish I was right at the accident scene with her head in my hands. And that would be a proper good-bye for me. I wish I could have prevented the accident from happening. I wish it was me instead."

For some participants the repercussions of their loves ones' dying also affected their grieving. A. was preoccupied with finding a replacement for her deceased boyfriend. C. and P. feared death. D. had the additional loss of being disconnected from her family as her mother maintained this connection for her. H. and I. had to leave their familial homes and move into group homes. C., E. and I. said that their most recent losses caused them to think back to the other people in their lives that had died or to those they no longer had a relationship with. E. and L. both grappled with a sense that life was no longer meaningful after their loved ones' deaths. For both, death took away the people which gave personal meaning to their lives. With L.'s father's death he could no longer be his "shadow" and as E. stated about his loved ones:

> "I'm not prepared to go through another one. If my mother or step-father dies, life isn't worth living. When (my sister) died, a part of me died. When my grandfather died, another part of me died."

All participants suggested one or more of the death concepts of irreversibility, inevitability, and causality. I did not set out to specifically ask the participants about death concepts, they were referred to as we discussed their death experiences. A participant may have understood death concepts in addition to the ones he or she mentioned.

4.5.2: Superficial Explanations

This category addresses the participants' explanations of death. Most of the participants' explanations reflect fatalism ("We all die sometime") or some form of religiosity ("It is God's will").

The participants' fatalistic and religious explanations of death parallel the explanations they received concerning their social and life events in that they are superficial explanations which minimize personal impact and significance and eclipse their questioning. The explanations of death which they receive are just as superficial as when they are told they are engaging in an event because they will be "happy" doing so.

The death of their loved ones had altered, for many, their sense of security and their sources of love and acceptance. Fatalistic and religious explanations may not answer their questions and concerns and they do not allow the participants' <u>own</u> explanations to be expressed. Some of the participants appeared to be saying, "Okay, people die because [insert explanation]..., BUT, how does that explain why my loved one died?"

Eight participants' religious explanations of why people die referred to going to "live with God" and "going to Heaven" which is described as a "new home". Five participants' fatalistic explanations referred to death as "a part of life," as happening to "everybody" and occurring when it is "time to go". P. referred to an explanation of causality saying that people die when they cannot eat or drink anymore.

4.5.3: The Why of Death

While explanations of fatalism, religiosity and causality provide an answer to why people die, such explanations are not the by-product of the participants' inward questioning of death. These explanations are not the result of the participants engaging in existential grief work. As such they do not appear to carry personal meaning for the participants or address for them the significance of the loss they sustained.

While the participants' grief included an outward expression of their loss and they could say who died, what biologically caused the death, when the death happened, where the death happened and where people go after death, the existential question of "why" people die was eclipsed. The focus on an existential "why" concerning death was suggested by the following.

I asked each participant to tell me what caused their loved one's death. Because I was not purposely using specific wording in this question, I wound up asking two different questions; one implied that I wanted to know what the loved one died "of " (causality) and one implied I wanted to know an existential explanation for "why" the person died. I basically asked the participants: "Can you tell me what your [loved one] died of?" and "Do you know why your [loved one] died?" I didn't expect two different answers to these questions, since I thought I was asking the same thing with both of them.

During the analysis of M.'s transcript I noticed that I had been asking two different questions when I asked about the cause of a loved one's death. For the sake of response validity, I did repeat various questions to the participants to ensure I was getting a consistent response. The first time I asked M., "Can you tell me what your dad died of ?" he answered "cancer". The next time I asked him a question concerning causality I unintentionally worded it differently:

> Stephanie: Do you know why he died?
> M: I don't know.
> Stephanie: Do you know what he died of ?
> M: Cancer.

After realizing that I was actually asking two questions, one about causality and one about an existential meaning of death, I re-analyzed the transcriptions to see what other participants answered when I specifically used the word "why" in relation to death. After re-analysis I discovered that I had used five different words to address causality: "why," "of," "how did," "because" and "from." No matter how the question of causality was put the participants responded with a biological cause of death. Re-analysis, however, also showed that the existential question of "why" death happens was referred to by five participants outside of the context of causality. Their statements follow.

When I asked F. if he thought the grief of "handicapped people" (his terminology) was different he said:

> "They do (grieve). But they don't understand because people don't explain them. Mom and Dad passed away, they wonder why. They want an answer. Nobody will ever answer the question. A doctor might say to you, your Mom passed away with a heart attack. How do you accept that. You have to be very...because a handicapped person, you don't know, cause you got to have patience to sit down and say...put it on the table."

F. also said:

> "They don't all understand because parents don't have...the patience to explain. It's not very fair with a handicapped person to not talk about their mother's death and their father's death and they might...they don't understand and she don't explain it the right way."

Although F. often used the word "explain" it seemed apparent that he meant two-way communication.

L.'s sister, Mrs. R., stated that in the days following the car accident in which L. witnessed the death of his brother-in-law, L. became frantic. She explained the incident as:

> "He said, 'Why do people have to die?! And get killed?!' And he was flailing his arms and was jumping around and was really weeping and yelling. He said, 'Why did (the brother-in-law) have to die?! Why did he have to die?!' Like he was reliving the whole bad adventure. And of course I was glad that our sons-in-law were there because they held him in their arms and said, 'That's the way life goes. Bad things happen to good people.' "

Concerning her brother N.'s grief regarding the death of their sister twenty years ago Mrs. W. stated that she thinks he has many unanswered questions of "why":

> "I don't think anything ever has been in perspective for him. I think he needs to do that for his own peace of mind. I don't think he understands what happened. And the whole process was just like: it happened, it was gone and then it was forgotten about. And I really don't think he had a chance to process any of that information. I mean we (the siblings) were confused. We could actually ask the questions and we were confused. I can imagine what he was going through and is still going through. We just told him to quit feeling...No, we don't have time for that. But I think and see this is the problem."

Mrs. W. also stated that N. "is in fear of death" because no one has ever talked about death with him.

E. stated that since his sister's death he has thought: "Why this? Why that?" He also said he has questioned himself: "Why did I rob them (his sisters) of their childhood".

D.'s sister, Mrs. X. and H.'s father, Mr. J., both suggested an existential questioning of death on behalf of their family member. However, where Mrs. X. accepted that D. could ask this question just as Mrs. X. has, Mr. J. denounced that H. would think about death in this way. Mrs. X. stated:

> "So maybe she is the same as I am. She could be sitting in her room right now thinking about her (their mother) and saying, you know I'm empty, why are you going."

Conversely to Mrs. X.'s acceptance that D. could ask why her mother died, Mr. J. stated of H.:

> "I don't think H. really does (question), if she does it's within herself. I don't think she questions why it happens, how it happens, it's just that it has happened and they have gone to Heaven, that's all."

The total picture of the participants which emerged is one of people who grieve within the confines and expectations of their social context. They appeared to be given just the information about death they were expected to need. No allowance is made for their personal questions, as Mr. J.'s statement attests. If I had specifically differentiated between a question of causality and an existential question about death what statements, questions or ideas would the participants have shared?

Chapter Five

5.1: Conclusions

A conclusion was reached to this study's main research question posed in chapter one. It is concluded that the social experience of being developmentally disabled does create a disadvantaged state from which to approach grief.

The form of this disadvantaged state became apparent when the participants' social experiences and life events were held up to their grief experiences. What emerged was a parallel between how they experience their social and life circumstances and how they grieve. The disadvantaged state from which they approach grief is the same as that from which they meet their social and life experiences. It simply, but profoundly is, the condition of lacking opportunities to process their thoughts and feelings and ask questions which bring personal meaning to their experiences.

This disadvantaged state develops from social experiences which deviate from the general population in conjunction with not having the opportunity to discuss these experiences. While I initially proposed that the disadvantaged state is internal, involving an affected ego state, it appears instead to be external and related to one's social context. That the participants did have fragile egos was likely a function of living in a social context which does not allow them to process or to have a say in their social and life circumstances. Just as their social contexts defined how involved they were in determining their lives, their grief is also defined by what their social contexts will bear.

The social experiences of the participants carried a secondary meaning as circumstantial losses. The social experiences and life events maintained their status as losses because they were not processed. If the participants had had the opportunity to process their thoughts and feelings about their social and life experiences, these experiences may not have been maintained as losses which affected their personality development and self-concepts. The significant issue within the participants' personal loss histories is not just which events took place but how these events were addressed.

Like their social experiences, their experiences with death are treated superficially. It is probable that parents and other care providers think that giving succinct explanations will reduce anxiety. However, giving fatalistic and religious explanations to account for why a loved one died is more likely useful for the purpose of reducing anxiety around death issues within the parents and care providers. These explanations may not address the personal questions and concerns the participants have concerning death or their circumstantial losses.

5.1.1: Discussion

Social Experiences

The participants' social experiences included those suggested in the literature. All participants had experienced social rejection and the stigma of name calling. All participants had experienced social deprivation and were segregated in terms of their education and social activities. All, except for one, had experienced segregation within their living arrangements. Seven participants moved from their family homes to residential care when they were children; three moved into residential care as adults after a parental death; two moved into residential care as adults because one was depressed and one was sexually abused. Only one participant asked to move from his family's home to residential care after he saw his younger brother leave home for college.

The move from the family home, particularly for participants who left home at an early age, did appear to represent the "hub" of their loss experiences as discussed by Kauffman (1994). Social relationships were significant by their absence. All participants had few, if any, friends. Some developed social strategies (Wilson, 1970) to attract friends including one who would stand on the street and wave to passing cars, one who would walk up to strangers and introduce himself, and two who retained the addresses and phone numbers of all they met and two who initiated telephone calls. For most, their friends were represented by their direct-care staff and their room mates or people they worked with in segregated work environments. All participants had low social support and no access to individuals who could offer objective counsel as mentioned by Reiss and Benson (1989).

Most had little contact with their siblings. For most, contact with parents was limited. Seven participants had surviving mothers; of these, five had some degree of contact with their mothers and two were shunned. Four participants had surviving fathers. Of these one visited her father every two weeks, two were shunned by their fathers and one had been abused by her father but had maintained a relationship with him.

Two had no surviving immediate family members and three had strong relationships: one with her father and two with their sisters.

All of the participants had an alertness or an anxiety about maintaining their exiting relationships. For one participant, the dissolution of two significant relationships caused him to twice attempt suicide.

None of the participants were in intimate relationships. Of the participants who had a boyfriend or girlfriend, only one considered his girlfriend, now deceased, as someone he would have married. The remainder, who were all female participants, appeared to consider their boyfriends not as someone with whom to live in matrimony but as symbols which signified their "normal" status. Ten participants used family photographs as substitutes for real relationships with their families and three had relationships with inanimate objects, one a television, one his parents' furniture and one his twenty year old radio.

Most of the participants experienced social disruption in either the form of having many residential moves, with no residence ever being guaranteed as permanent, or by experiencing staff change-over at their residential agencies.

The social experience of failure was the hardest issue to explore with participants. Only two participants spoke about realizing they could not do certain tasks and one spoke about worrying that he will make mistakes. Most of the participants spoke of how they "helped" others rather than how they failed. Interviews with family members revealed that some participants were protected from even having the chance to fail.

While most appeared to have been protected from failure all were infantilized as described by Reiss and Benson (1984) in that they were not asked for their opinions and their personal decisions were made by others. Five of the participants' infantilization included their mothers' treatment of them as "babies."

The issue of parental acceptance was raised by four family members. Only one mother appeared not to acknowledge that her son has a disability. Three parents did not accept the behaviour of their disabled adult child. The mothers of five participants expressed guilt; these were the same mothers who regarded their adult children as "babies."

Most participants lacked the typical markers of maturation as spoken of by Langness and Levine (1986) and MARC (1995). Eight participants did not know their ages or the year of their birth, two participants referred to markers of high school graduation and another of his twenty-first birthday. One participant insisted he was two years younger than his actual age.

Familial sexual abuse was experienced by one female participant and one other female participant was suspected to have been sexually abused by a house mate.

The participants had experienced "socio-cultural" (Edgerton, 1984) disadvantage. While they did not live in overt poverty, each received a form of government income-assistance. Most experienced restricted opportunities in the areas of employment, housing, education and leisure.

5.1.2: Personality Development

The personality characteristics of the participants included those discussed by Zigler (1975). As discussed by Zigler and Burack (1989), the participants' socialization histories did include specific factors which contributed to specific personality characteristics. The significant factors in the participants' socialization histories which contributed to their personality characteristics included: social disruption; social deprivation due to the breakdown of relationships with family and others; segregated living and social rejection. Histories of infantilization to the degree where they were stripped of having opinions and making their own decisions and communicated with only didactically also contributed to producing the four discernible personality characteristics of: seeking social attachments; dependency and acquiescence; and passing and denial.

The personality characteristic of passing and denial which Edgerton (1967) calls donning a "cloak of competence," was evident in each participant to varying degrees. This personality characteristic in particular demonstrated the participants' struggle with social comparison, their socialization for reduced social competency and their awareness of their differentness. Most used the protective coping strategy of attributing their difficulties to less stigmatizing conditions. Six did not identify that they had a disability. Only one participant accepted that she was "just a little bit retarded". However, she preferred to say she was mentally challenged as she had proven to herself and to others that she could engage in challenging sports events and be successful. Four engaged in the coping strategy of comparing themselves favourably to those who were lower functioning. Five tried to avoid others with disabilities.

Specific examples of the personality characteristic of passing and denial which four participants demonstrated included one who used a magazine as her photo album and who also placed on her bedroom wall a frame with the pictures that it came with as she had no others to replace them; one carried and referred to an empty change purse; one was elated to have been laid-off like the rest of his fellow employees from his community-based job; and one participant engaged in what he thought was expected male behaviour by referring to females as "Babe" and "Good Looking". Five participants also engaged in the coping strategy of impression management, referring to their clothing, hairstyles or possessions in an effort to draw attention away from their disabilities.

In addition to donning identities which are meant to hide their disabilities, some participants were said to don "situational identities" (Zetlin & Turner, 1984; Cegelka & Herbert, 1982). Some participants were said by their direct-care staff and family members to use their disabilities to make themselves seem more dependent than they are.

5.1.3: Self-Concept

As suggested within the literature, the participants' self-concepts were defended (Edgerton 1967, cited in Wilson, 1970). Although the participants had many relationship losses, to say that their self-concepts were "perilously riddled with losses" as Kauffman (1994) suggests is an overemphasis. The participants did not seem defeated, they wanted to be seen as successful and useful and had not given up on making relationships.

Although it was said by one family member and it appeared to be true for the other participants that every person who entered participant L.'s life was a loss because they never met his expectations for a relationship. The reason for the multitude of dissolved relationships and lack of intimacy appeared to be as much the participants' fault as it was the people with whom they sought relationships. As much as the participants may be blamed for being "socially incompetent" (Edgerton, 1984) the same blame can be shouldered by the people with whom they sought relationships. These people tended to avoid contact in lieu of being clear about when they could be contacted; they did not provide relationship boundaries which would have given the person with the developmental disability control and social competency within the relationship.

The areas from which the participants' self-concept characteristics were drawn were similar to those that Baroff (1991) discussed. The participants' self-concept characteristics addressed the domains of intimacy, success and self-determination — all domains which were inadequate in their lives.

This study's findings agree with Jahoda et. al's (1988) assessment that interpersonal experiences are the main variables affecting self-concept. The participants' interpersonal experiences indulged their dependency and dulled or eclipsed their ability for personal authority; specifically the ability to have intimacy, to have opportunities to be successful and to have the autonomy to make their own choices and decisions.

Most participants did not have intimate relationships with family or friends. The extent of poverty in their relationships led some to cling to family photographs while others maintained relationships with inanimate objects. Some invented strategies to find friends or, as one participant did, made do with fictional relationships. Only one participant mentioned that she had ever had a relationship in which she felt that the other person knew how she felt "emotionally on the inside".

The participants also expressed their desire for relationships and intimacy through their favourite songs, movies and television programs. The participants' "theme" songs expressed love, marriage, relationships and happiness. Their choice of movies and television programs also carried themes which expressed something about how they viewed themselves.

The lack of self-determination in the participants' lives was identified in their not making or even knowing that they could make their own decisions. Most participants did engage in outer-directed problem solving as discussed by Zigler (1975) and they commonly spoke of waiting to ask staff if they could do something; waiting to see what a parent would have to say; and saying they were "told" by others that they could do something.

As mentioned, the participants did not seem defeated by the failures they had experienced, especially in their relationships with others. Possibly because they have continually been given the message that they are the ones who need help, they wanted to give me the impression that they are successful, that they do help others, that they could be successful and helpful if given the chance. Many participants re-framed their actions with others so as to suggest that they were helpful. For example, many said that instead of "working" at their work placements they "help out" there.

5.1.4: The Concept of Death

All of the participants expressed grief in relation to the death of a significant other. What is concluded concerning their grief pertains to the type of grief they expressed. The participants expressed reactive grief, an outward orientation concerning the loss of a relationship. What was not included in their grief was an internal orientation or an existential questioning about death. The grief of the participants included the concepts of causality, inevitability and irreversibility. They expressed knowing the "who, what, when, and where" concerning the deaths they had experienced. That is: who died; what the biological cause of death was; when he or she died; and where he or she died as well as where they went after death. It is interesting to note that only three had a definition for the word "grief."

A few participants questioned why death happens beyond the concept of causality. Just as Seltzer (1989) believes that limited cognitive ability does not pre-empt loss from occurring in one's life, some participants' in this study suggested that they can ask why death happens and that they would benefit from making personal sense of death.

Reactive and existential grief exist in the grief process of most humans. The suggestion that poor abstraction abilities may rule out the possibility that the grief of people with developmental disabilities includes internal questioning would be to suggest that their grief is qualitatively different than for the general population. A few participants in this study suggest otherwise. Rather than it be the case that the participants in this study did not think about this question, I think their social context barred them from such questioning. They did not have the opportunity to raise their questions or concerns because they were provided with succinct explanations of death such as causality, fatalism or religiosity.

To suggest that people with developmental disabilities be invited to ask the existential question of why death happens as part of their grief work is not to suggest that they will reach a definitive answer; after all, no one has the definitive answer. Rather, inviting them to question why death happens provides for the process of opening up a discussion about their concerns, thoughts and feelings raised by the deaths they have experienced, as well as about their past, unprocessed, circumstantial losses. It provides an opportunity to process the personal issues that death raises for them and it may enable some to develop their own personal explanation of death. Whether definitive answers are arrived at, or can be arrived at, is secondary to the opportunity to process one's questions and concerns.

If the participants in this study had the opportunity to incorporate an internal, existential questioning about death within their grief work they might have gained the opportunity to process their personal questions about death and their circumstantial losses. The personal issues which arise from the collected information — which are eclipsed by didactic explanations of causality, fatalism or religiosity — provide practice implications which could include the following. Would A., C., D., H., K., N., and P. process the sense of abandonment death raises for them? Would I. wean himself from alcohol if he could process his shame about his disability and thinking that showing dependency suggests he is disabled? Would B. and O. process the sense of injustice they carry on their shoulders? Would L. process his loss of security and constancy and sense of desertion? Would E. process his guilt and sense of failure? Would M. gain coping skills which relax his sense of carrying on with life just the same no matter what crisis erupts? Would F. process his love and his hate for his mother and be able to enjoy guilt-free freedom?

Three participants had received death education information through their workshop placements. It was said by direct-care staff that these participants had not retained the information. Possibly there was low retention because of the way material was presented or because it did not address the personal questions and concerns of the participants. One other participant received counseling about death and dying when her father thought he was dying.

Some of the situations outlined in the literature concerning how people with developmental disabilities are protected from death were experienced by the participants. While none had been excluded from attending the rituals surrounding death all had had the impact of the death experience minimized in their lives primarily, it would seem, because no one wanted to talk about the death or it was thought that talking about the death would create anxiety for the person with the developmental disability. From family member interviews, their occasional avoidance of death-related issues, topic-changing and instances of crying, it was evident that the topic of death created anxiety for some of them which prevented their talking about death.

5.1.5: Listening for Their Questions

Some participants in this study were asking the general question "Why?" in relation to information they were given about the events which unfold in their lives. Some wanted more information. It may be that the participants in this study tried to ask the question "Why" about their concerns but that they were not heard or they were not listened to.

This study suggests that the onus is on those involved in the lives of people with developmental disabilities to look at the individual ways of communication and self-expression used by people with developmental disabilities. Two participants in this study expressed anger and confusion about their circumstances in divergent ways. One expressed this through kicking his pregnant sister in the stomach and another flailed his arms, wept and verbalized his question "Why?"

Other participants also communicated in personal ways. There was self-expression through depression, suicide attempts, alcoholism, sexual abuse, rigid adherence to a personal routine and one participant was said to engage in "silent communication".

The style of communication the participants seemed to have experienced and were still immersed in was one of didactic discourse. They did not appear to experience two-way conversations where they had decision-making ability or the ability to offer their opinion or state their questions. Parents and care providers appeared to think it was necessary to provide the participants with answers or directions. Possibly the parents and care providers thought they themselves needed to look as if they had all the answers.

5.2: Methodological and Ethical Concerns

A few of this study's methodological choices helped to involved the participants more personally in the interviewing process. The creation of the life event documents <u>with</u> each participant was important for the control it allowed the participants to have with their disclosed information. Although each asked me to write down their information, before information was added to their "pictures" as most called them, I asked each participant if I could record the information and where it should go on his or her picture. When each participant and I reviewed the documents for <u>my</u> mistakes or to add more information, each was eager to do so and a few chose to add additional information. Some thought so much of their pictures that they had them framed.

The tape recorder I chose for interviewing also proved to be helpful in allowing the participants control during the interview process. At first I was going to use a hand-held sized tape recorder thinking that it would less obtrusive; I ended up using a large recorder instead. The buttons on the larger recorder were bigger, as were the audio cassettes and the participants could easily put their own tape in and out of the recorder and turn the recorder on and off and pause it if they wanted to.

When used, the semi-structured questions each proved helpful in retrieving specific pieces of information from the participants. In general, the questions were helpful in addressing issues of the particpants' passing and denial, social comparison, stigma, failure and low aspiration for change. While the fifth question, which concerned an experience with death, was helpful in finding out information about their experiences with death only two answered the question as I put it, by saying whether they thought their disability affected their grieving. Participant F. said it had and participant E. said it had not. The remainder of the participants, possibly to avoid talking about their disabilities, answered the question by referring to how they were included in a funeral or a memorial service.

While the semi-structured questions were instrumental in constructing a picture of the participants' phenomenological worlds, the majority of the interviews were conversational with the participants initiating topics of discussion. A question contributed by a participant regarding the use of song lyrics proved valuable for gaining a better glimpse into the inner, personal desires or beliefs the participants had about themselves.

Response validity was a methodological concern in this study. It was because I repeated various questions to the participants to ensure I was receiving consistent responses that this study's conclusions pertaining to internal grief work emerged. Since I was repeating questions during interviewing, my attention was drawn to how I had been asking two different questions when I asked about the cause of a loved one's death.

A methodological concern was raised regarding informed consent. My initial consent document made provision for obtaining concurrent consent, the coupling of direct consent of the person with a developmental disability with the permission of a guardian. I planned to first inform the guardians about my study and obtain their permission to allow me to ask the person with a developmental disability to consent to participate. In addition to Parkes' (1995) ethical guidelines, I reasoned that guardians should be informed and should give permission due to the potential risk of temporary emotional distress to the participants.

One referring agency questioned my plan to obtain concurrent consent. In their opinion, concurrent consent contradicted their principle of encouraging self-determination. Concurrent consent, I was told, promotes the dependency of people with developmental disabilities. A plausible point from the perspective of normalization, but within the paradigm of consent, the agency possibly was not giving equal consideration to each of the three elements of consent — capacity, information and voluntariness.

To address this issue of self-determination versus capacity to give informed consent, I revised my consent document to include two protocols allowing me to obtain either concurrent or direct consent. Concurrent consent was to be obtained from participants under the age of majority (age 18) *or* if the developmental disability precluded the capacity to engage in rational decision-making. Direct consent was to be obtained from participants over the age 18 with the capacity to engage in rational decision-making. Determining "capacity" was the responsibility of the referring agencies since they would better know the participants' capabilities.

All fourteen participants gave direct consent. The effectiveness of consent received from each can be questioned, to some degree, on each of the three elements of consent. "Voluntariness" appeared to be overshadowed by the desire to please and to be included. Eagerness to please was most evident when I reviewed the consent document with each participant. Each wanted to decline the right to withdraw or refuse to answer. Some agencies considered the participants' ability to sign their names and their situational capacities — the ability to follow certain routines/directions — as demonstrating "enough" capacity to give direct consent. Most of the information about this study's purpose and their rights as participants appeared insignificant to the participants. Most seemed to hear only that this study offered them a chance to talk about a loved one's death and to be a "teacher" about their lives. The power of the words "death" and "teacher" showed me the potential for certain words to unethically influence participation.

This study has raised the dilemma of ensuring both self-determination and the effectiveness of direct consent. A potential resolution is a two part, direct consent procedure similar to that of Turnbull (1977). This method allows the researcher to determine the ability to give consent based on her inquiry, rather than on the opinions of others. As this consent method directs the researcher to first address the person with the developmental disability it does not presume incapacity or dependency.

The first step of this method would involve giving the referred participants, aged 18 and older, information about the study in a meaningful manner. For example, I used simple language, repeated words when necessary and, when needed, had someone known to the participant aid mutual comprehension between the participant and myself. In the second step, participants would be asked to reiterate the information disclosed to them such as the research procedures, risks and benefits, and their responses would be recorded. Their responses would make evident the adequacy of their understanding and indicate if direct consent was sufficient.

Evident from this study is the researcher's responsibility to first address people with developmental disabilities to determine their ability to give direct consent; to be able to substantiate the effectiveness of the consent obtained; to obtain a second party's consent if the adequacy of direct consent is lacking; and to consider the extent to which participants with developmental disabilities are accustomed to making significant decisions.

5.3: Recommendations

This study has five recommendations. This study emerged with a picture of people with developmental disabilities ensconced in environments with people who talk at them rather than with them. It is recommended that those close to people with developmental disabilities invite and encourage questions and engage in two-way processing of information and also actively listen for the overt as well as latent questions before responding.

The issues of helping people with developmental disabilities attain and maintain relationships through using relationship boundaries appears to be important. Relationship boundaries for personal space, telephone, writing, etc., may help to reverse the pattern of having every person they meet becoming a loss and help them to establish relationships with longevity.

A third recommendation would be to seek grief counseling from an objective support person rather than expect direct-care staff to cope with the grief of a resident. As participant D.'s experience attests, a direct-care staff person may have his or her own grief issues which intrude into the grief work of the resident and which cause the resident's grief to be directed rather than supported.

A fourth recommendation suggests a practice implication. The importance of involving those people who share a common history with a person with a developmental disability such as family members, guardians or significant others which could include staff persons, within the grief work of a person with a developmental disability was indicated by this study. Involvement of such individuals within the grief work of a person with a developmental disability would complement a counselor's attempt to consider the social elements within the griever's past and present environment.

A last recommendation would affirm the conclusion reached in this study that the grief work of people with developmental disabilities should be encouraged to include both reactive and existential grieving. Rather than asserting that their grief cannot include internal questioning because of difficulties with abstraction or because no one has the answers to questions they may raise, the existential question of "why" should be allowed to surface. By doing so, the concerns that a death raises for them, as well as their past circumstantial losses, can be processed.

5.4: Limitations

Three limitations of this study concern the sample population and the methodology. The strengths of the sample population included an almost equal proportion of males to females, every decade between the ages of twenty to seventy was represented, the sample was drawn from three geographic locations, the participants had diverse residential living experiences, and had differing experiences with death. The drawback of the sample population was that all of the participants were from the same cultural background. It would have been interesting to have had participants from other cultures involved for their contributions to how their social experience of developmental disability may have differed as well as for differences concerning grief responses and explanations of death.

A second limitation concerned the number of family members who participated. Of the seven participants who did not have a family member participate, direct-care staff stated for three of them that if their parents knew of this study they would not want their adult child to participate. Of the other four, one had no surviving parent or any siblings and the other three were not close to their families. As well as offering a different perspective, family members were valuable for the historical insight they provided.

The third limitation concerned the wording of the third interview question. On reflection, this question as worded could be considered a "leading" question. The question asks the respondent if he or she thinks that society has treated him or her "differently." The word "differently" presupposes the respondents' experience of societal treatment and could have potentially influenced their response to this question.

5.5: Future Research

Future research is necessary to explore the quality of the grief work engaged in by people with developmental disabilities, in North American culture and other cultures. Does the grief work of people with developmental disabilities lack more than an opportunity to engage in internal grief work? Are there other areas of grief work presently "off-limits" to people with developmental disabilities?

Another grief-specific research idea would be to study peer counseling on the topic of grief, including grief regarding death and grief regarding unprocessed circumstantial losses. In this study, six participants possessed the potential to be a peer counselor. Besides having experienced a death, they were empathic, were thoughtful in their expressions about death and they wanted to help others by sharing their own life experiences.

A future research idea lies in exploring the modes of self-expression used by people with developmental disabilities. Along with self-expression which is generated from within the individual, what are the external sources by which they may express themselves? This study's use of favourite songs, movies and television programs contributed to my understanding of the participants' desires and self-perceptions.

Two additional research ideas concern including people with developmental disabilities as research participants. One is to generate qualitative research methodologies which give the participant an active role with decision-making capabilities within the research process. The other is to return to the agencies which supported this research to discuss the possibility of developing a research hand-book for agency use. A handbook discussing ethical and methodological issues as well as what return the participants and agencies could expect would help prepare agencies serving people with developmental disabilities for requests to participate in social research studies.

5.6: Conclusion

The conclusions reached in this study were not predictable at its outset. That fourteen people with developmental disabilities each contributed a part of themselves in the hope to teach others about their social experiences and experiences with death was for each a courageous and generous act. Their personal experiences chronicled here will serve as the foundation for future research. For their contributions it is not much for them to ask, as L. did, "Keep me in mind" as future research on this topic is undertaken.

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Appendix A

Consent Forms

Letter of Consent (I)

I, ________________________, agree to participate in the study being conducted by Stephanie Dell'Aquila on grief and developmental disability. I also agree to allow my child/dependent, ________________________, to be informed of this study and to be asked to give verbal, if not written consent, to participate if he or she so chooses. I understand that my participation will involve one personal interview of one to one and a half hours duration, which will take place in my home or the place of my choice. I also understand that my child/dependent will be interviewed, and these interviews will be the same length and not be more than four in number. I am aware that all interviews will be audio taped and that the tapes of my child's/dependent's interviews will be transcribed by a person who is experienced in transcription and is aware of issues of confidentiality. I am aware that all personal information will be kept confidential and all identifying information will remain anonymous. I understand that all tapes and the typed transcriptions of my child's/dependent's interviews will be kept in a locked place and destroyed once the report is completed. I am aware that I and/or my child/dependent may withdraw from participation at any time, and that I and/or my child/dependent may refuse to answer any questions.

Signed, ________________________________

Date: ________________________________

I would ________, would not __________, like a summary of the study results.

Letter of Consent (II)

I,__________________________, agree to allow my child/dependent,____________________, to be informed of the study being conducted by Stephanie Dell'Aquila on grief and developmental disability and to be asked to give verbal, if not written consent, to participate if he or she so chooses. I decline to participate in this study and I do understand that my participation would have involved one personal interview of one to one and a half hours duration, which would have taken place in my home or the place of my choice. I understand that my child/dependent will be interviewed, and that these interviews will be of one to one and a half hours duration and not be more than four in number. I am aware that all interviews will be audio taped and that the tapes of my child's/dependent's interviews will be transcribed by a person who is experienced in transcription and is aware of issues of confidentiality. I am aware that all personal information will be kept confidential and all identifying information will remain anonymous. I understand that all tapes and the typed transcriptions of my child's/dependent's interviews will be kept in a locked place and destroyed once the report is completed. I am aware that I and/or my child/dependent may withdraw from participation at any time, and that I and/or my child/dependent may refuse to answer any questions.

Signed, ____

Date: ____

I would______, would not______, like a summary of the study results.

Letter of Consent (III)

I, ________________________________, agree to participate in the study being conducted by Stephanie Dell'Aquila on grief and developmental disability. I understand that I will be interviewed, and that these interviews will be of one to one and a half hours duration and not be more than four in number. I am aware that all of my interviews will be audio taped and that the tapes will be transcribed by a person who is experienced in transcription and is aware of issues of confidentiality. I am aware that all personal information will be kept confidential and all identifying information will remain anonymous. I understand that all of my tapes and the typed transcriptions will be kept in a locked place and destroyed once the report is completed. I am aware that I may withdraw from participation at any time, and that I may refuse to answer any questions.

I give........., do not give,..........,Stephanie Dell'Aquila my consent to inform my parent/ sibling of this study for the purpose of asking for his/her participation.

Name:
Phone Number:
Relationship:

Signed, ________________________________
Date: ________________________________

I would........, would not......., like a summary of the study results.

Letter of Consent (IV)

I, ______________________________, agree to participate in the study being conducted by Stephanie Dell'Aquila on grief and developmental disability. I understand that my participation will include one personal interview of one to one and a half hours duration, which will take place in my home or the place of my choice. I am aware that my interview will be audio taped and then transcribed. I am aware that all personal information will be kept confidential and all identifying information will remain anonymous. I understand that the audio tape of my interview and the typed transcription will be kept in a locked place and destroyed once the report is completed. I am aware that I may withdraw from participation at any time, and that I may refuse to answer any questions.

Signed,______________________________

Date:______________________________

I would__________, would not__________, like a summary of the study results.

Appendix B

PART A: DEMOGRAPHICS

Demographics of Parents

Name:

Age:

Sex:

Cultural/Ethnic Background:

Religious Affiliation:

Family Composition:

Relationship to Participant with a Developmental Disability:

Relationship to the Deceased Person:

Demographics of Participants with a Developmental Disability

Name:

Age:

Sex:

Formal Diagnosis: Age at Diagnosis:

Developmental Age:

Cultural/Ethnic Background:

Religious Affiliation:

Education:

Type of Residence:

Relationship to the Deceased Person:

Appendix C

PART B: SEMI-STRUCTURED INTERVIEW SCHEDULE

- When these five questions were asked of parents/siblings, they were worded so that the parents/siblings were asked to give their personal opinions. I did not ask parents/siblings to speak for the participant with a developmental disability. I used the participants' descriptive terms such as handicapped, challenged, disabled, etc.
- These questions were asked as the live event document was being completed.
- In consideration that participants with developmental disabilities varied in receptive and expressive verbal skills, I adopted their language preferences and when a semi-structured interview question was asked, I endeavored to convey the question in wording which was the most meaningful to the individual.
- As this study intended to allow the participants to speak for themselves, these questions were used on a "need-to" basis. Therefore, it was possible that the I did not need to ask each of the five questions if a participant addressed the subject matter independently.

1. Which life events do you consider "happy" or "sad" and why?

- This question probes for a personal history of necessary and circumstantial losses.

2. Are you aware of having social experiences which are different from others around you?

- This question probes for personal, social experiences which are believed to be unique.

3. Do you think society (your family, neighbourhood, school, workplace) treats you differently because you have a [developmental disability]? How does that make you feel about yourself?

- This question probes for the awareness of differential treatment based on the condition of having a developmental disability. It also probes for self-evaluation.

4. What are the things you like and dislike about yourself or your life. What things would you change about yourself or your life if you could. How would others describe you.

- This question will probe for self-evaluation and the extent to which personal likes and dislikes about oneself are based on having a developmental disability.

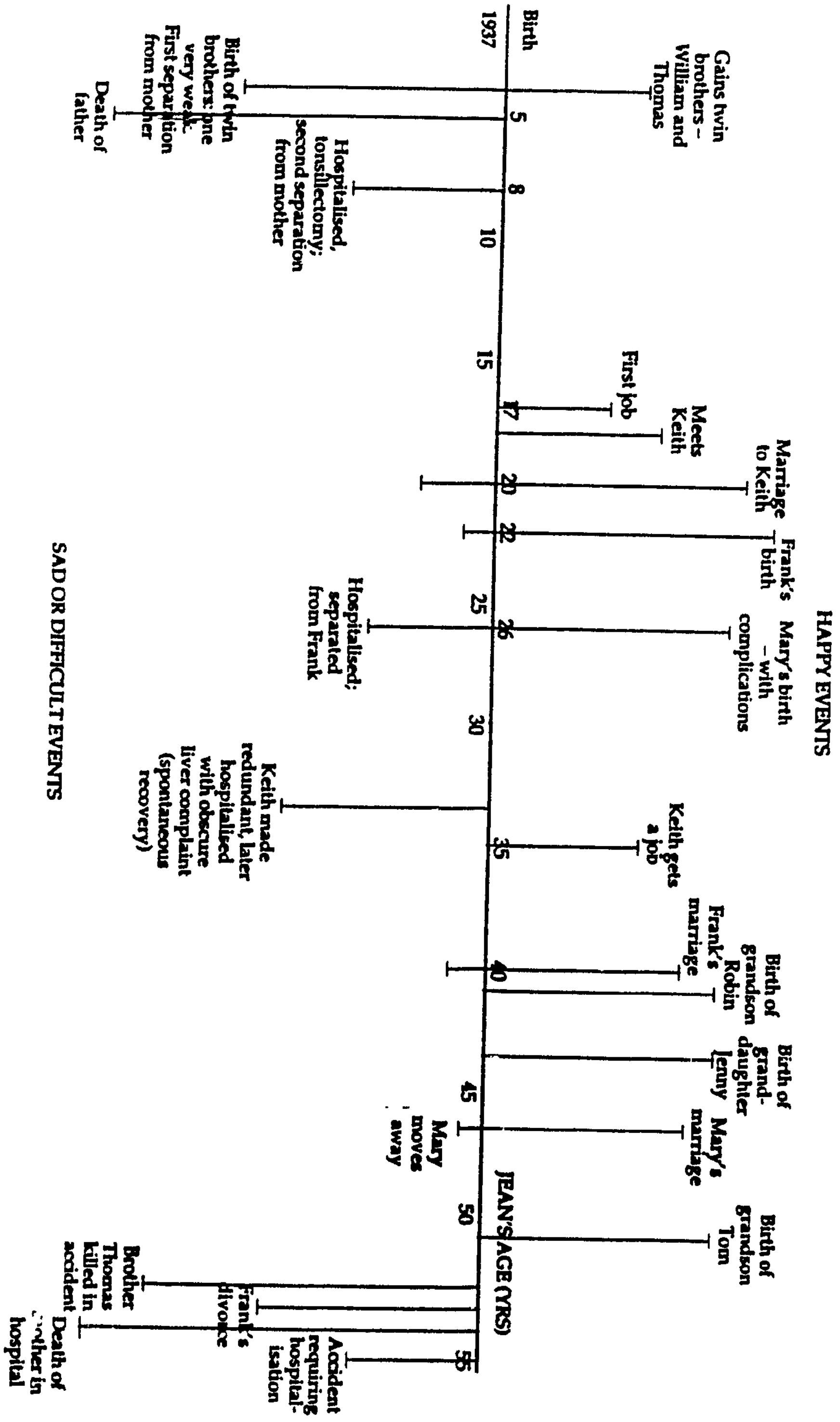
5. Do you think that having a [developmental disability] made any difference in how you felt when someone important to you died and in how you reacted to that person's death?

- This question will probe for understanding of the concept of death; understanding of the concept of grief; what kind of advice they would give to others who experience the death of a significant person; and, what is helpful and not helpful in dealing with grief, especially if one has a developmental disability.

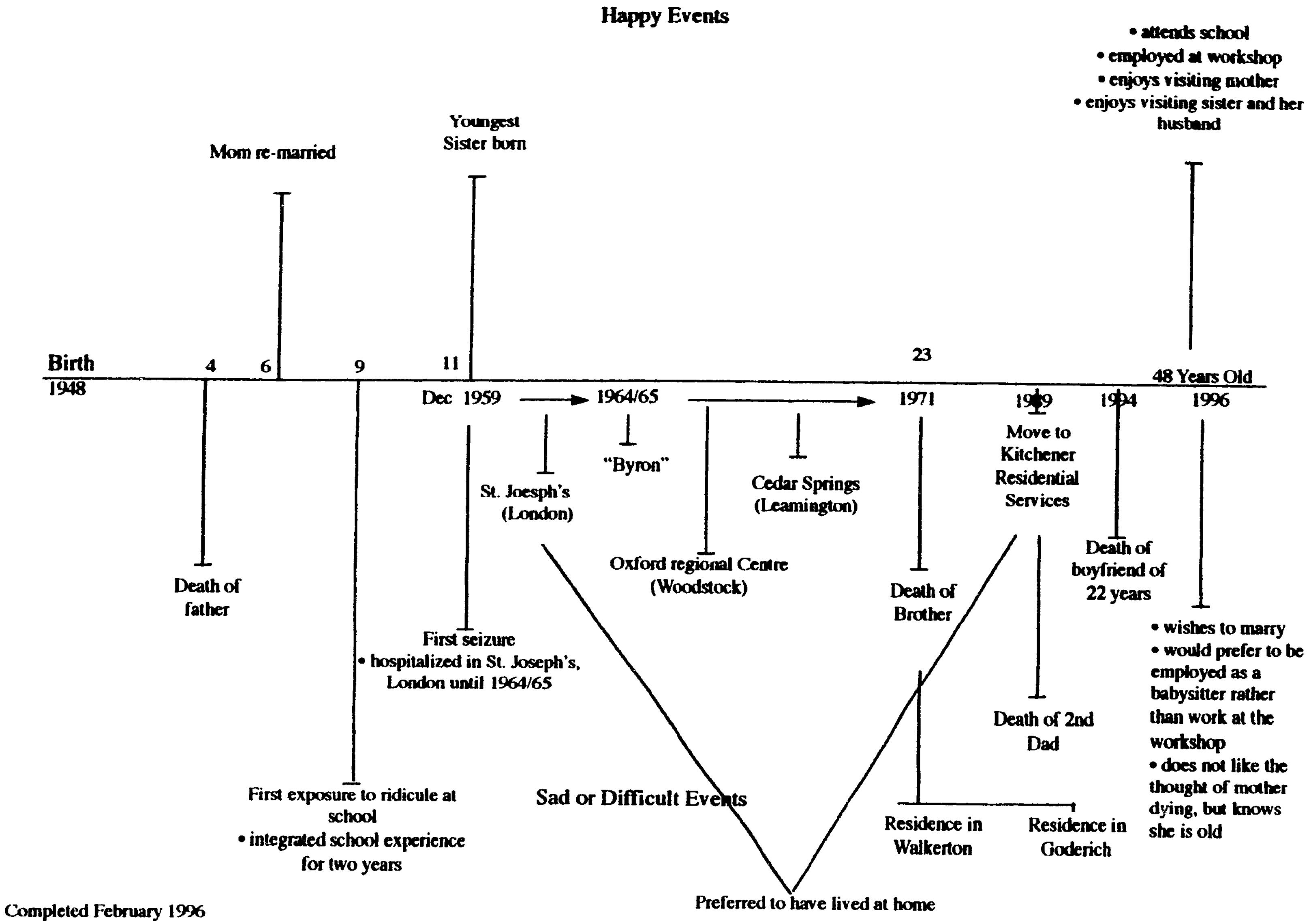
Appendix D

Sample Lifeline Document

Table 8.2 Lifeline of Jean

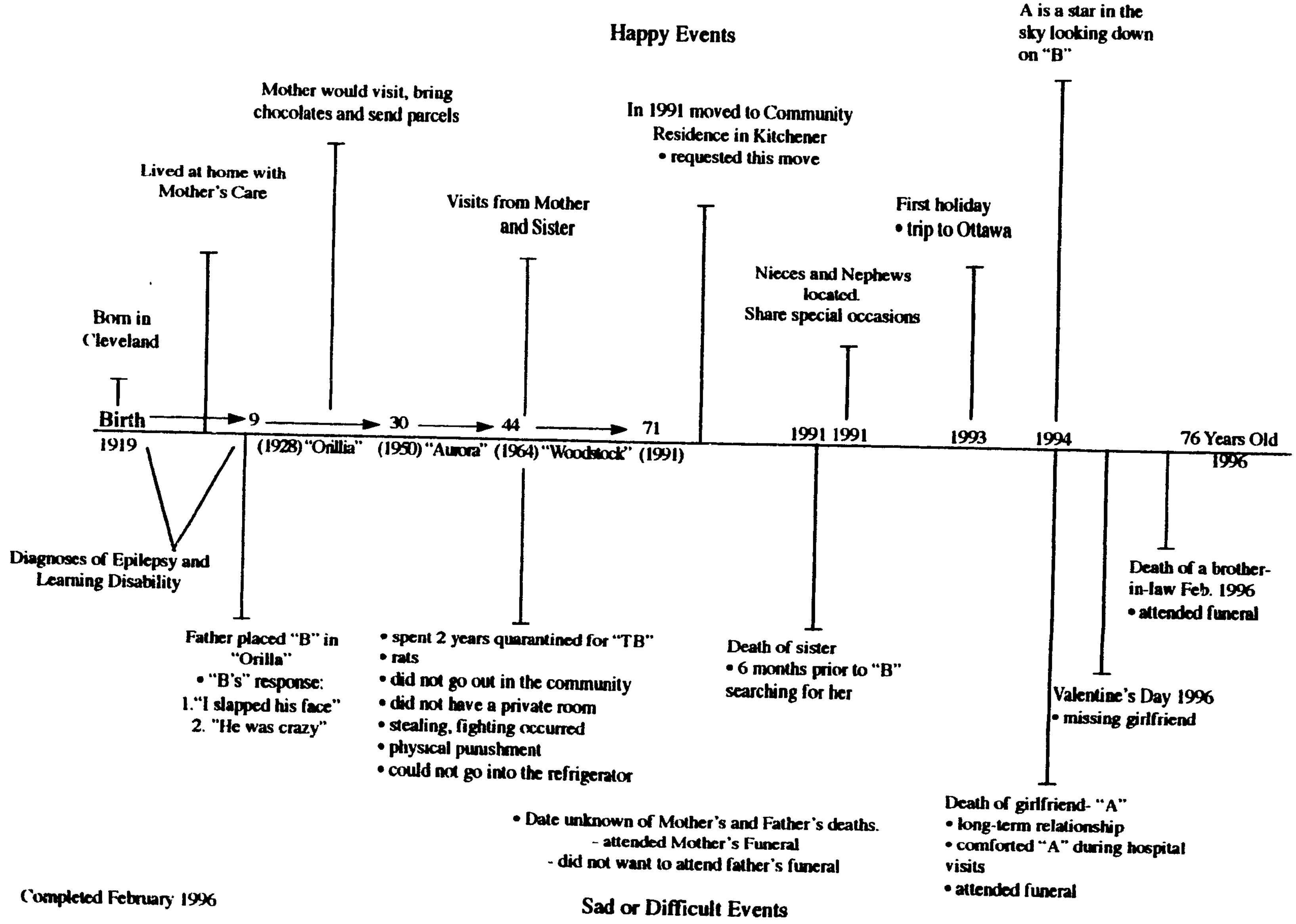


Lifeline of "A"



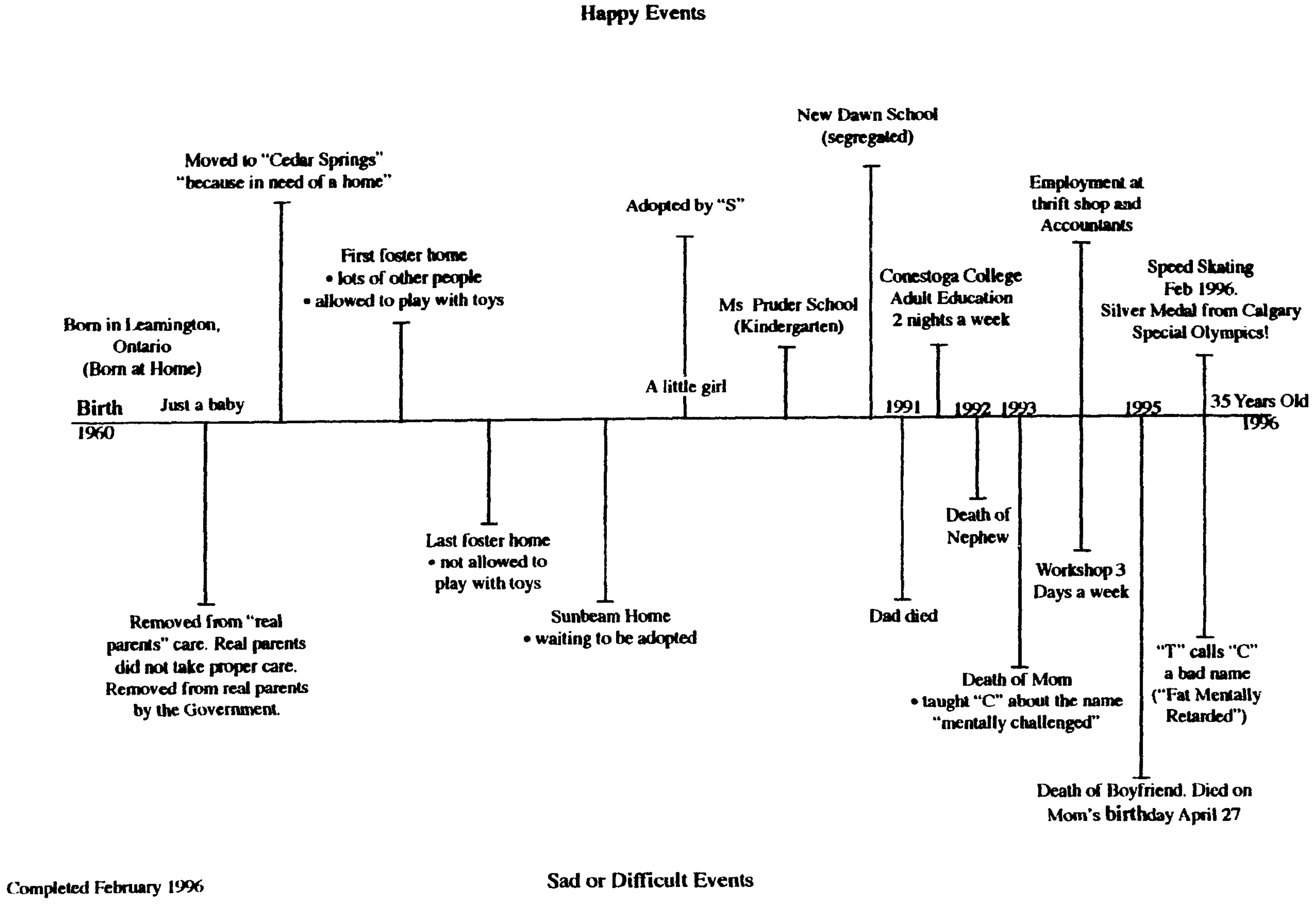
Completed February 1996

Lifeline of "B"

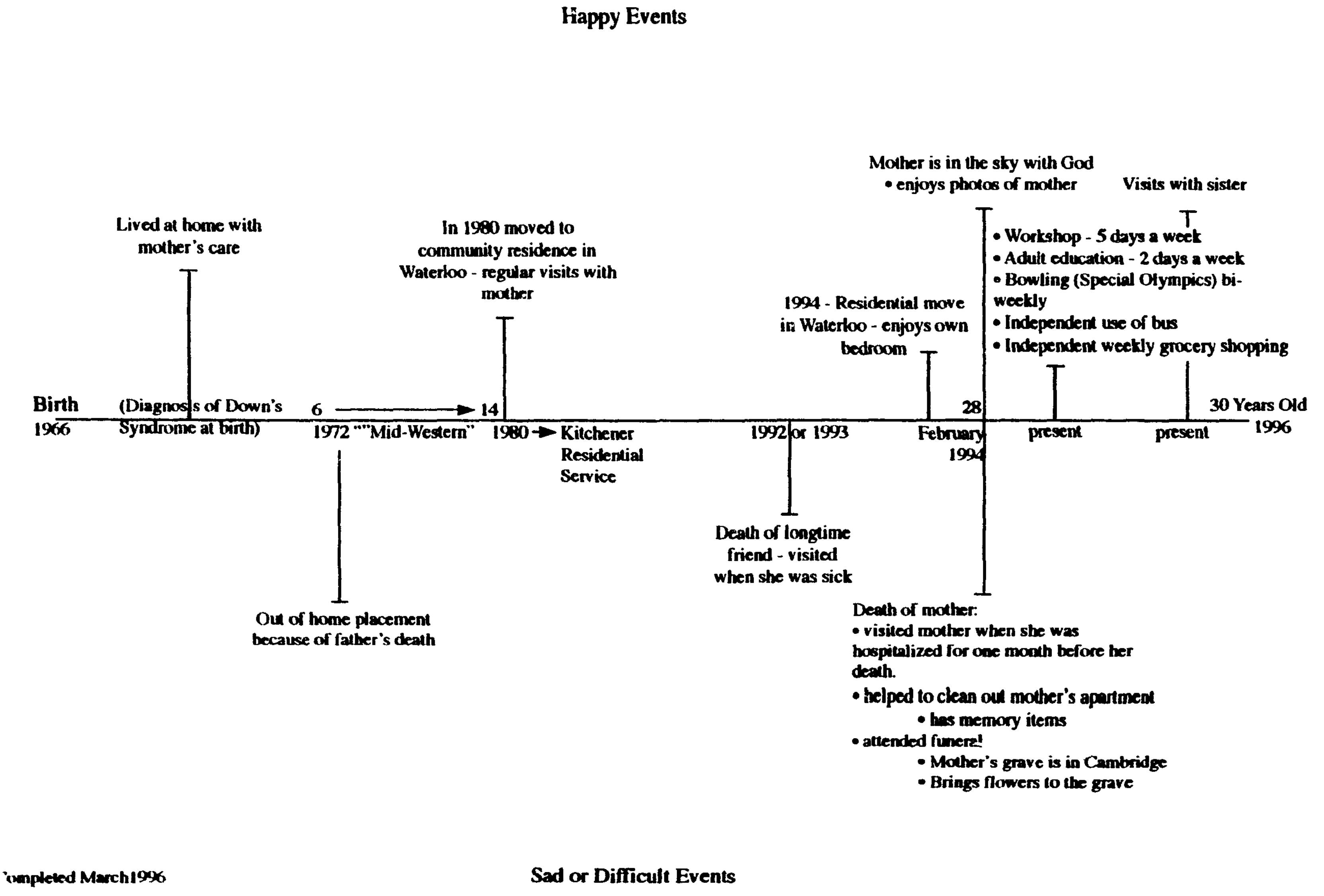


Completed February 1996

Lifeline of "C"



Lifeline of "D"



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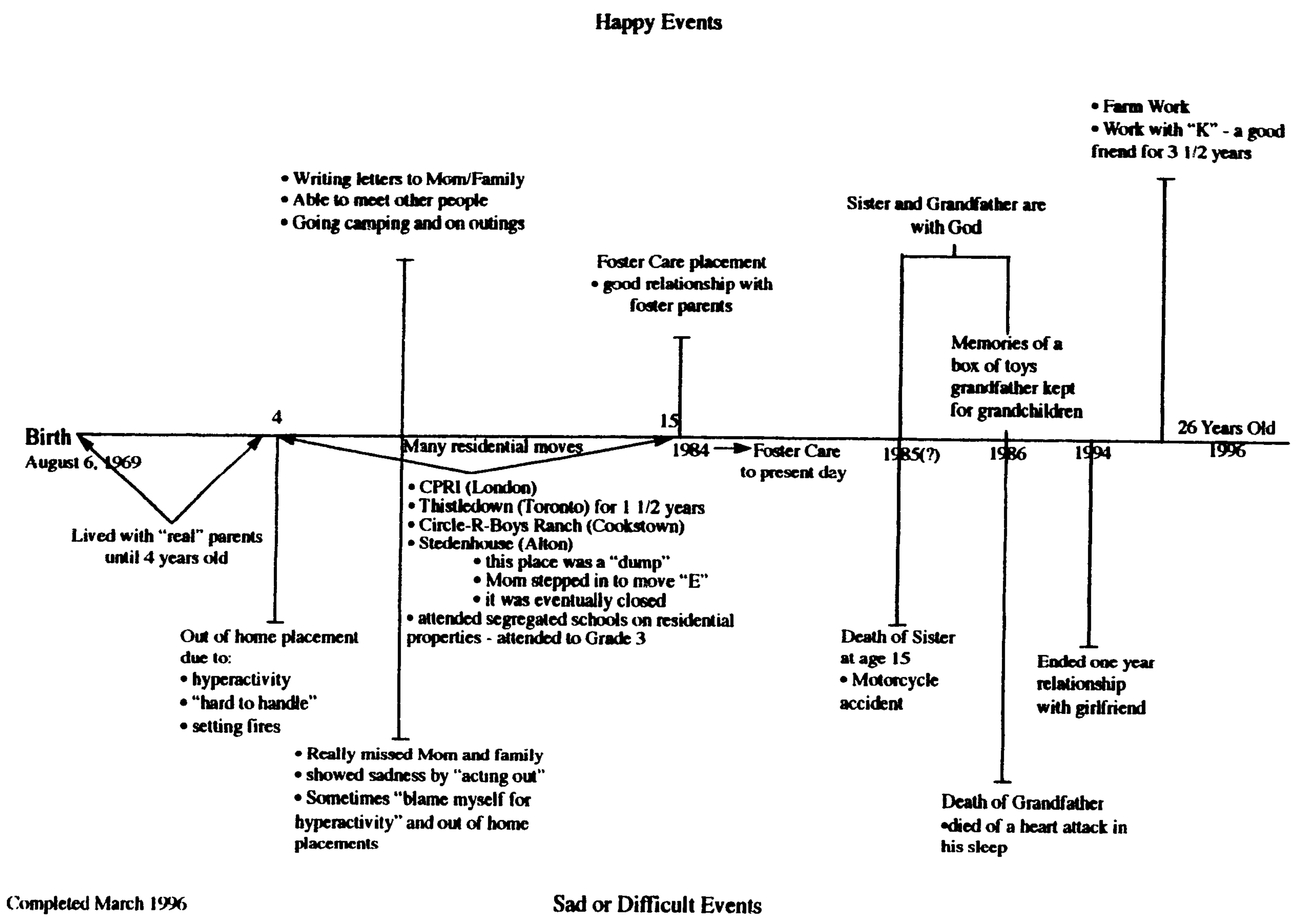
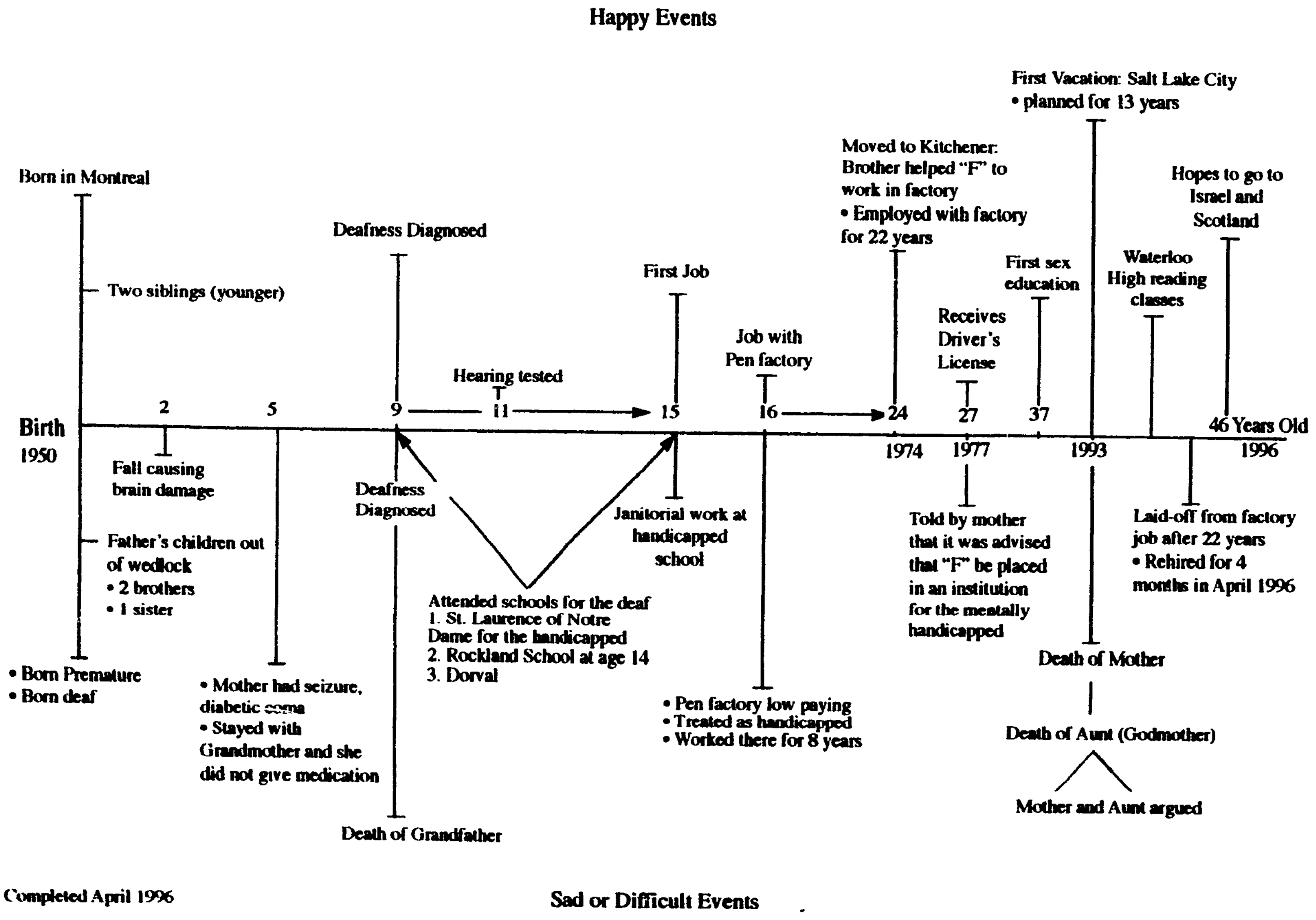
Lifeline of "E"

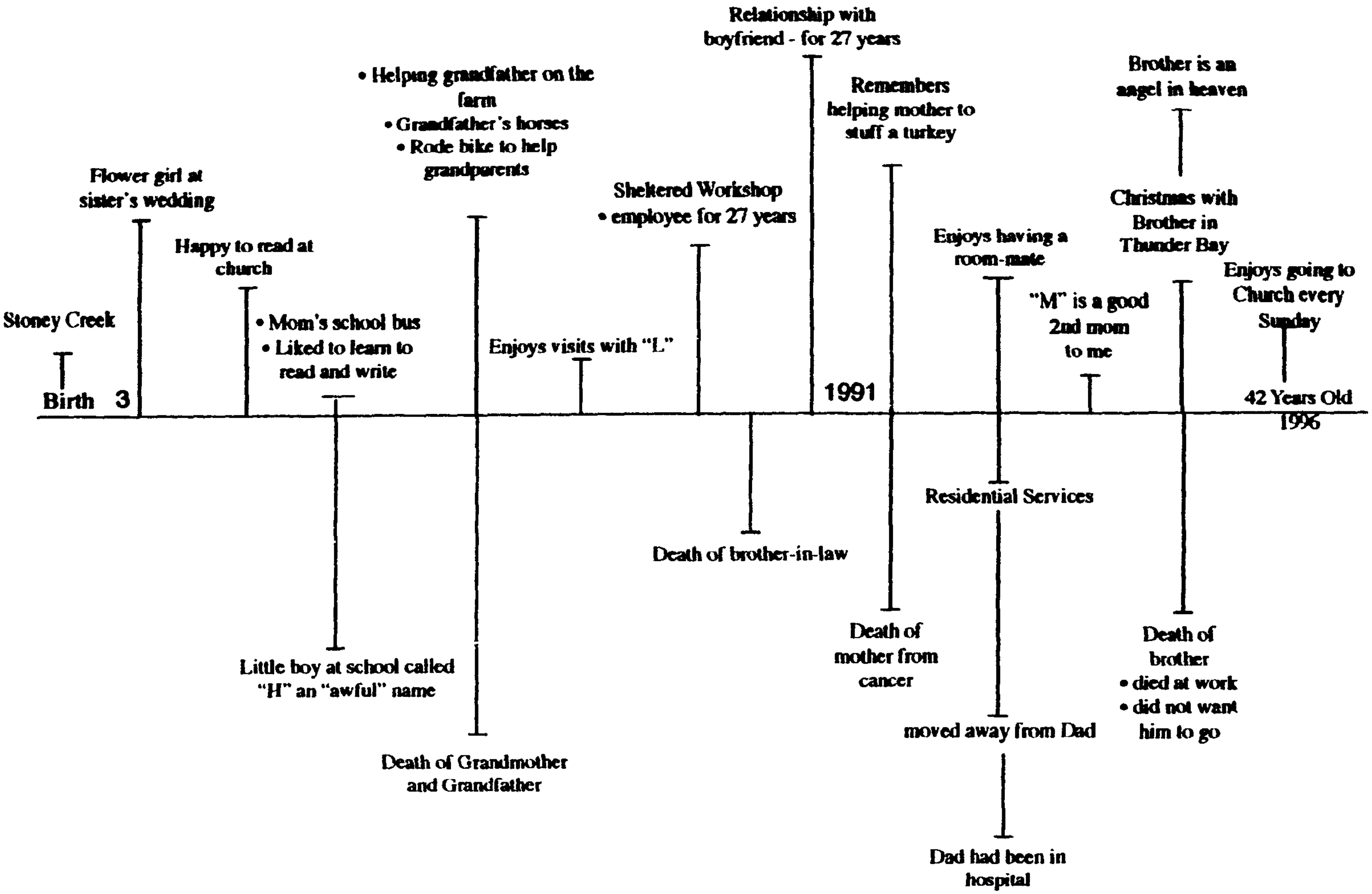


Lifeline of "F"



Lifeline of "H"

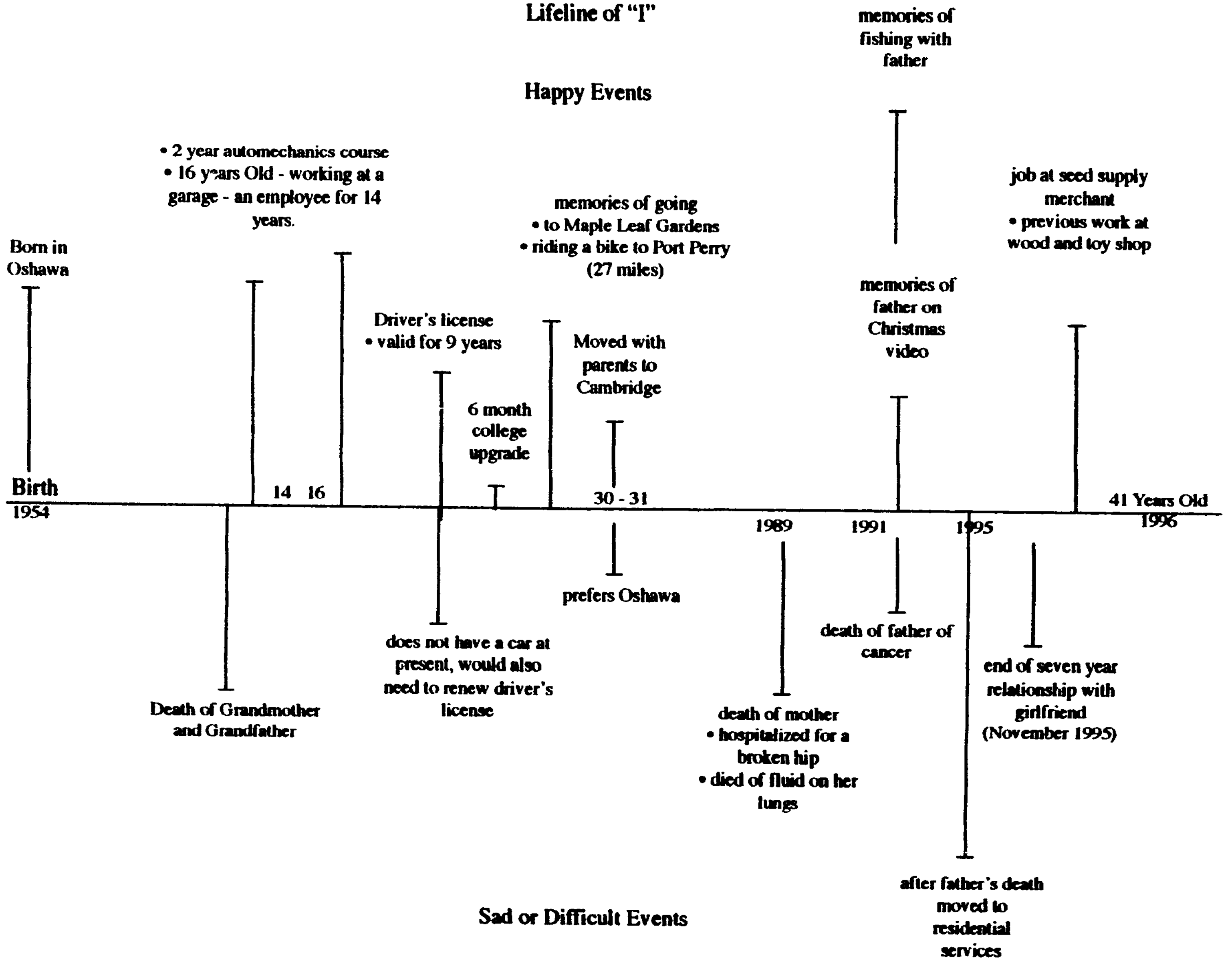
Happy Events



Completed May 1996

Sad or Difficult Events

Lifeline of "I"



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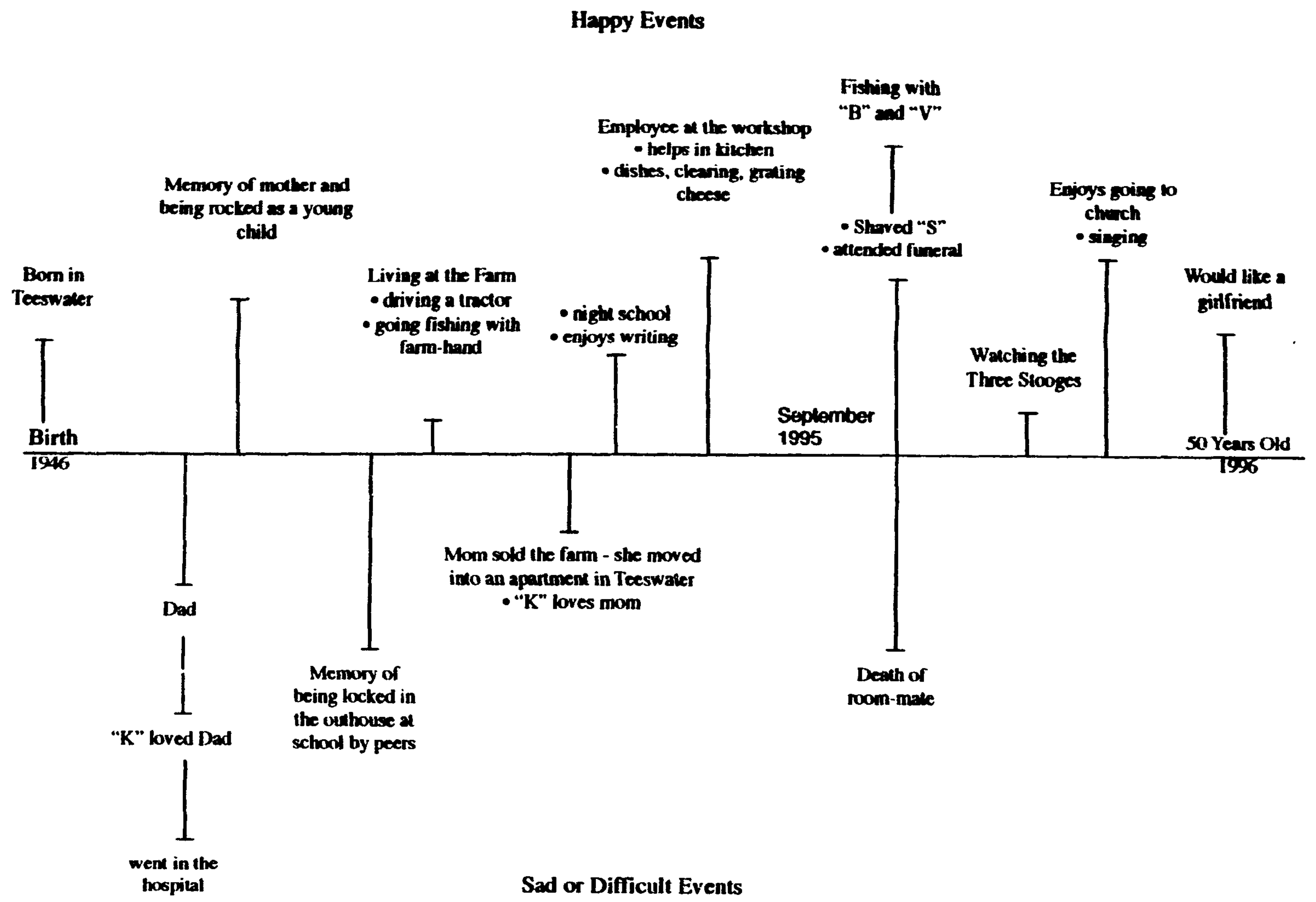
Lifeline of "K"



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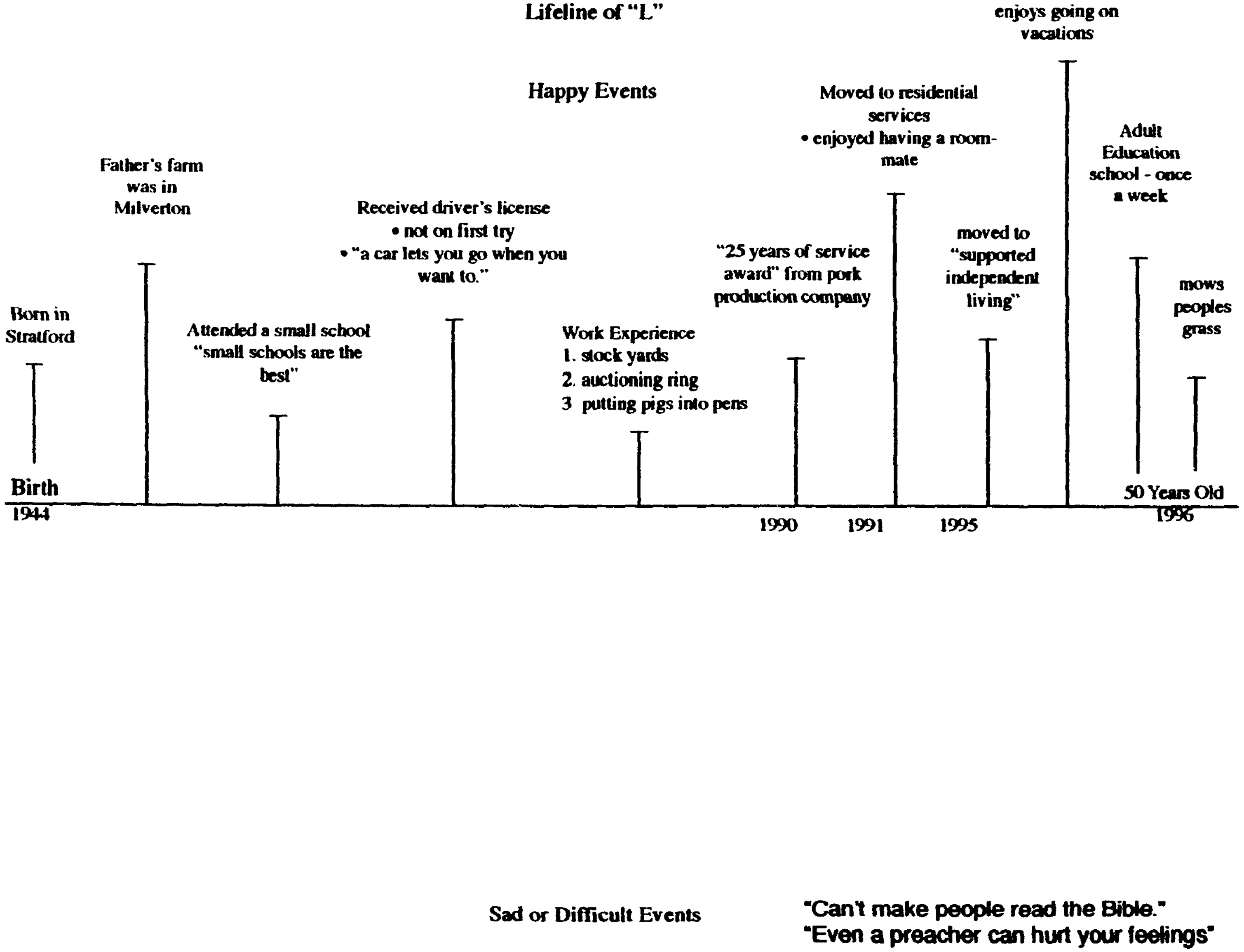
Lifeline of "L"



Completed May 1996

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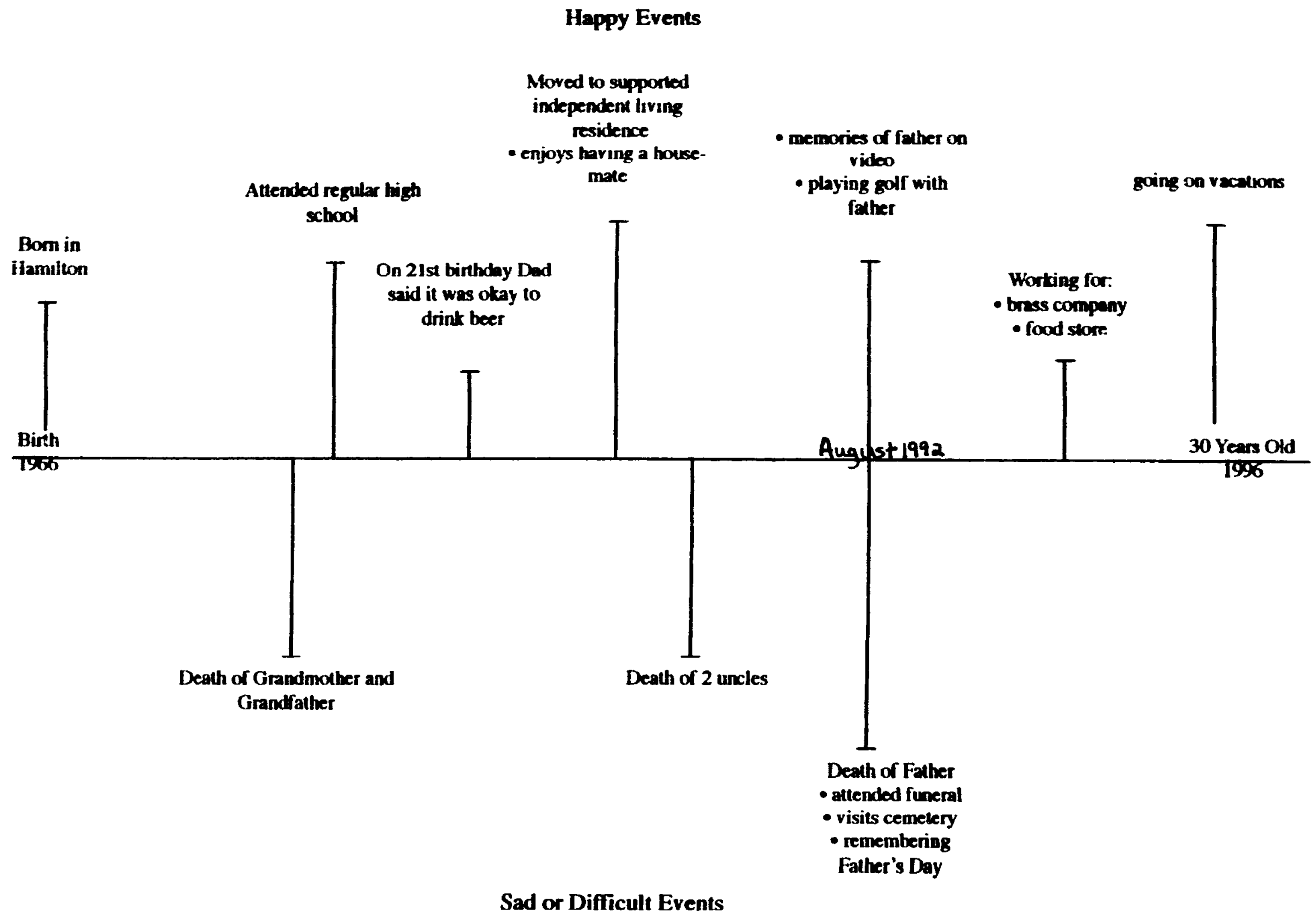

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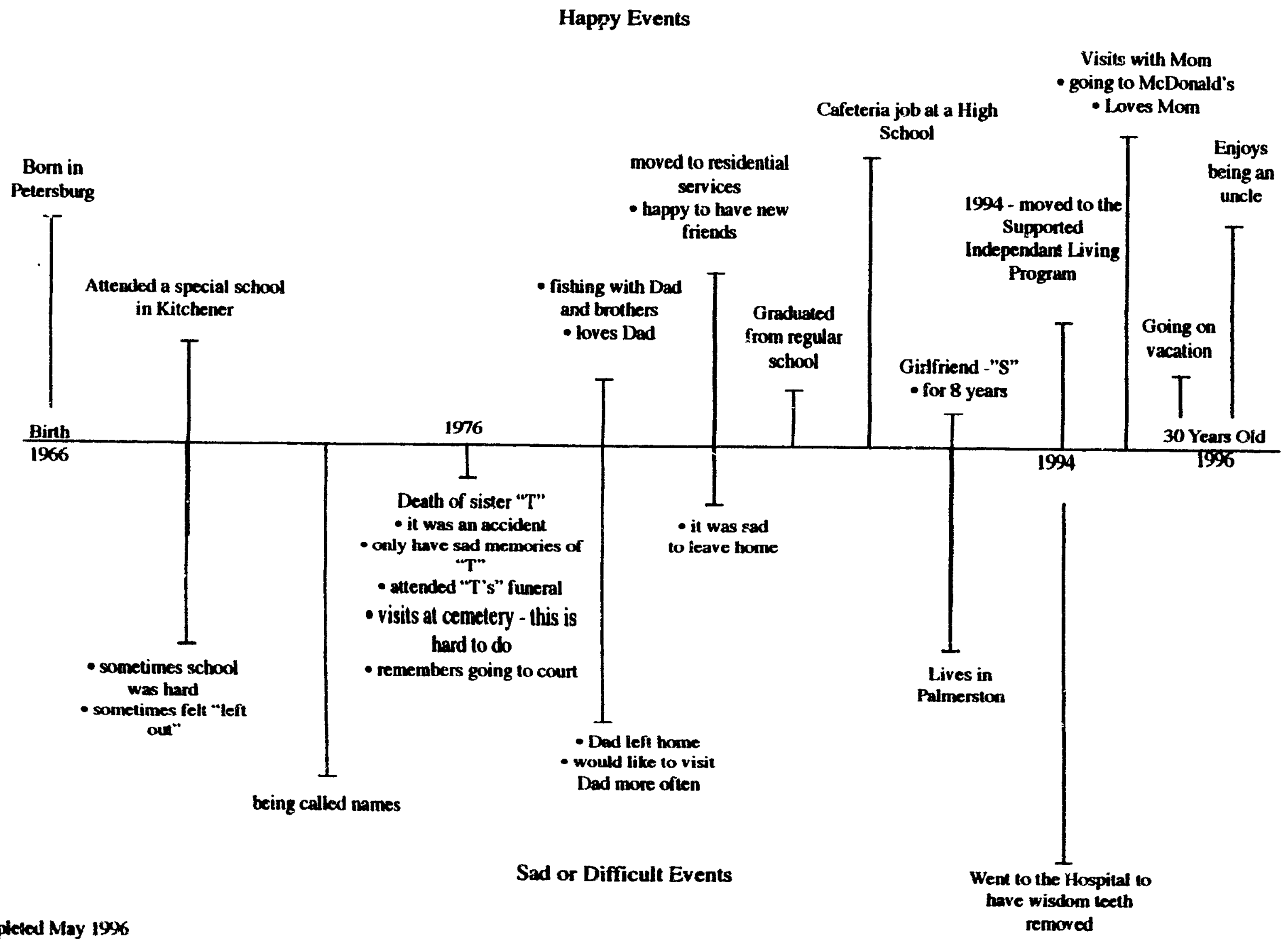
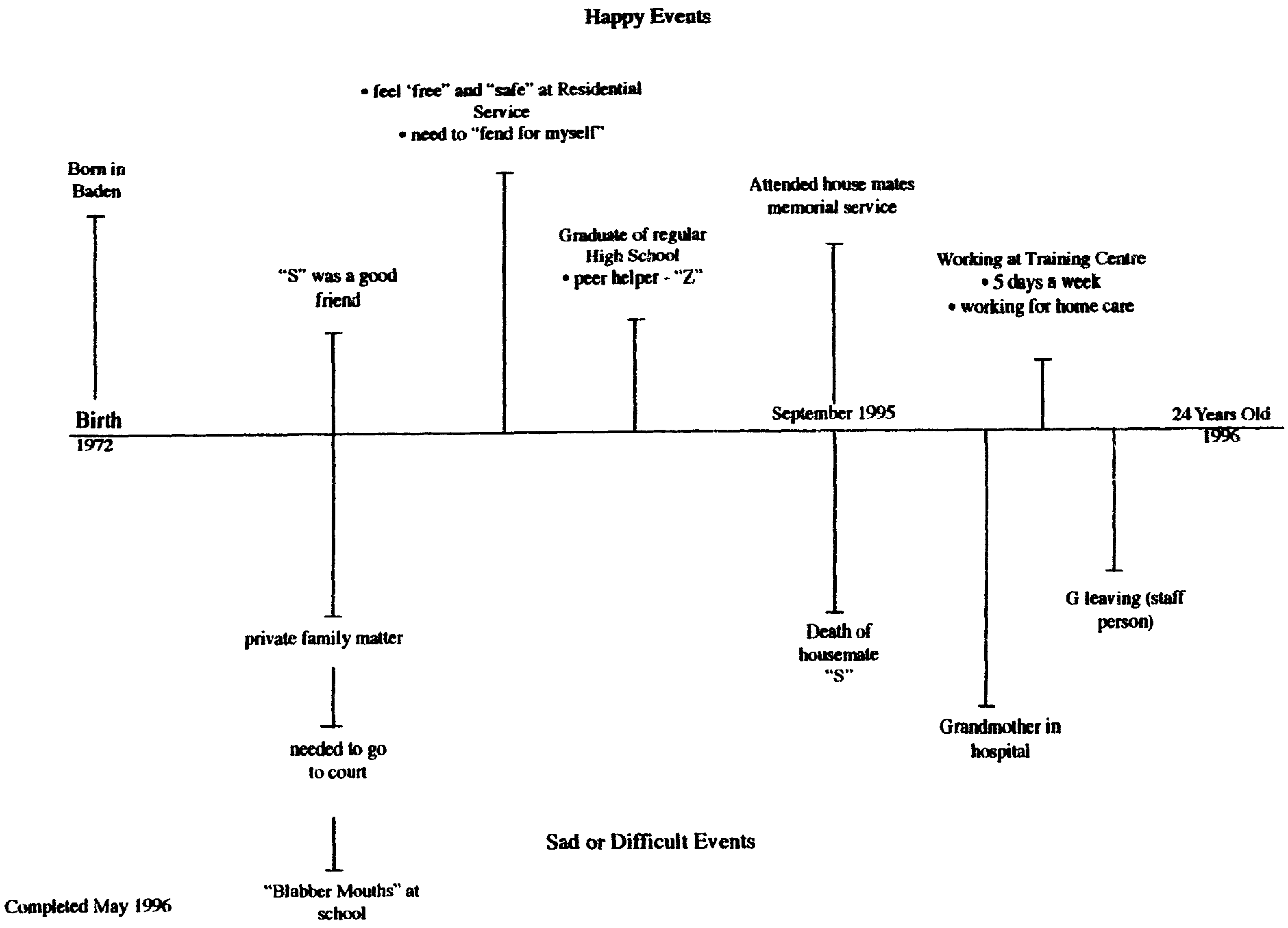
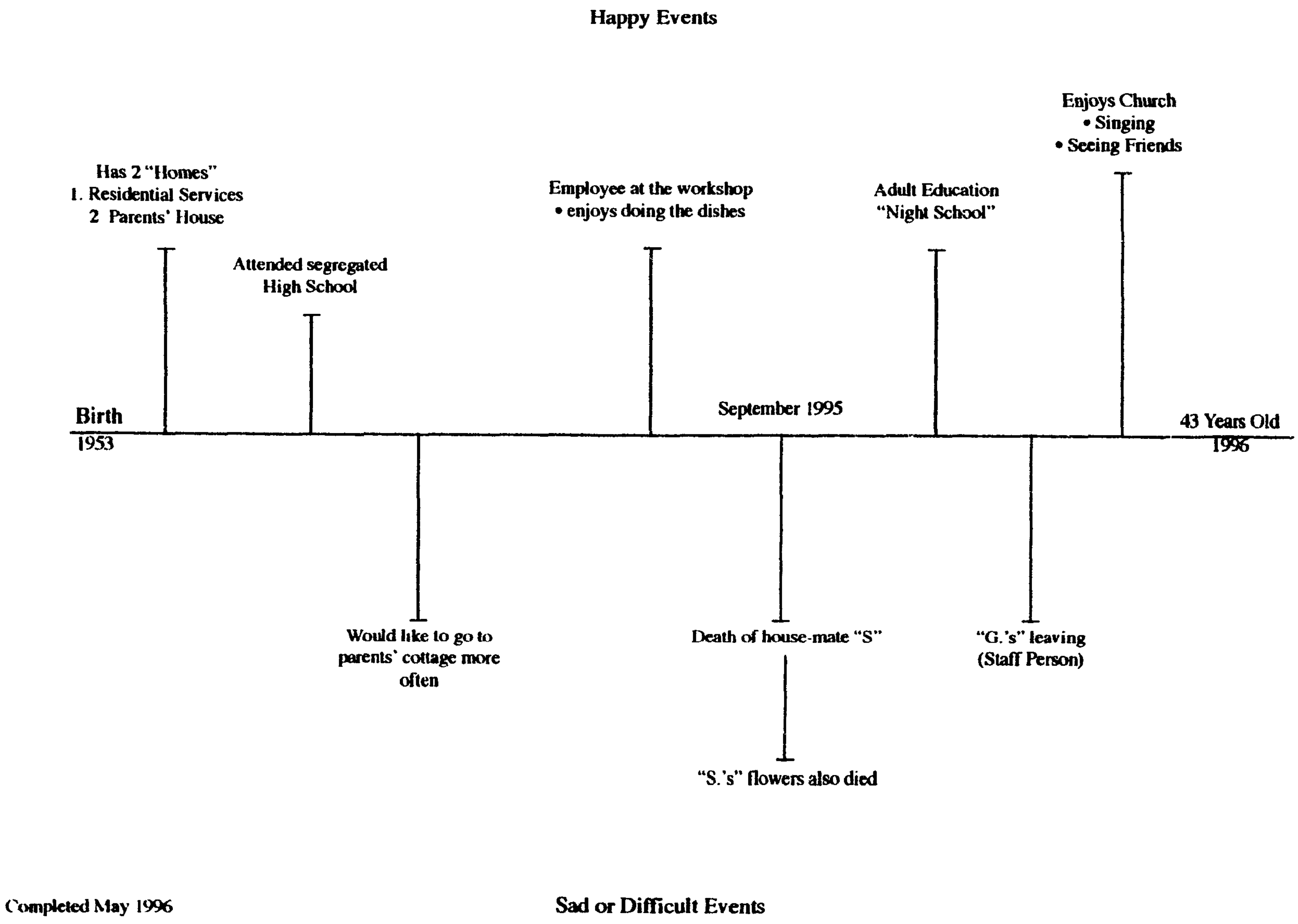


Completed May 1996

Lifeline of "O"



Lifeline of "P"



Appendix E

Social Learning Theory and Personality Characteristics of Expectancy of Failure

Julian Rotter's 1954 model of personality development and people with developmental disabilities derives from social learning theory (Ingalls, 1978; Rosen et al., 1977). The premise of this model is that relative to non-developmentally disabled children, developmentally disabled children experience more failure and, therefore, as they mature, they develop lower generalized expectancy of success (Rosen et al., 1977). This lowered expectancy of success becomes self-fulfilling and circular; as the person's expectancy to fail produces failures, expectancies of success are lowered as is belief in one's abilities.

Rosen et al. (1977) report that empirical research from this theory confirms that people with developmental disabilities: 1) do perform below their abilities; 2) relative to the general population the internalization of responsibility for the outcomes of their efforts are delayed, meaning they function from an external locus of control longer than their peers; 3) and after a failure experience they are less likely to try harder.

Piaget's Theory

Piaget's theory of intellectual and moral development as Rosen et al. (1977) suggest seems "tangentially" (p.192) related to personality factors. Piaget's theory in part relates developmental stages of moral development to stages of cognitive development. There is the potential that Piaget's theory can add to the understanding of the personality dimensions of self-control and socially appropriate judgment and conduct. This would be useful for teaching people with developmental disabilities social and life skills (Rosen et al., 1977).

Empirical studies of moral conduct and people with developmental disabilities are relevant in terms of personality factors, since one's level of moral conduct relates to "situations of temptation and situations in which behaviours of self-restraint and self-control are evaluated "(Rosen et al., 1977, p.193). Empirical studies from this theory document that relative to non-developmentally disabled people, people with developmental disabilities are no more prone to moral misconduct.

Psychoanalytic Position

What the psychoanalytic theory contributes to the study of personality development of people with developmental disabilities is that personality, temperamental and developmental factors influence mental growth and learning activities (Rosen et al.,1977).

Ingalls (1978) relates a Freudian orientation to developmental disability and personality by referring to ego functioning. People with developmental disabilities are said to have defective ego functioning since they are typically deficient in: learning about reality; understanding the consequences of their actions; and delaying gratification and controlling impulses so that they can release frustration in a socially accepted manner (Ingalls, 1978). Therefore, people with developmental disabilities are likely to be ruled by their impulses. As Ingalls suggests, the defense mechanisms they adopt to protect against anxiety such as repression and denial are typically primitive and not very effective. Consequently, irrational reactions and excessive anxiety predominant their dispositions.