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IDENTITY MAKING PROCESS OF INDIVIDUALS
WITH MILD INTELLECTUAL DISABILITIES

DISSERTATION

A Dissertation Submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the

College of Social Work

at the University of Kentucky

By Carolee Kamlager

Lexington Kentucky

Co-Directors: Dr. James J. Clark, Professor School of Social Work

University of Cincinnati

and Dr. Kay S. Hoffman, Professor of Social Work

University of Kentucky

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ABSTRACT OF DISSERTATION

IDENTITY MAKING PROCESS OF INDIVIDUALS WITH MILD INTELLECTUAL DISABILITIES

The shadow of stigma theory typically surrounds the research investigation of the lives of individuals with mild intellectual disabilities. McAdams' life story theory and methodology provide a human development framework as an alternative to the prevailing framework in the field of disability. This study moves out of the shadow of *otherness* and examines the personal identity making process of twelve individuals with mild intellectual disabilities in the light of human development theory. Findings dispel the assumption that individuals with mild intellectual disabilities construct their lives solely through their disability. Rather, the identity making process includes the influences of socio-cultural events, religion, mentoring, advocacy, and the lived experience of disability.

In this study, twelve adults with mild intellectual disabilities completed adapted life story interviews and four quantitative measures to explore the themes and patterns of agency, communion, redemption, contamination and generativity. Additional qualitative analysis expanded the range of discovery for influences in the identity making process. Following analysis of the quantitative scores, interviewees were placed in either the Higher Generativity Group or Lower Generativity Group. Analysis occurred at three levels: within case, within group and between group.

Differences between the groups emerged, such as, involvement in human rights advocacy, presence of mentors and spiritual guides, and religious beliefs. Human rights advocacy provided a rich source of generativity and meaningful connection to others, politically, socially and emotionally. Turning point narratives often contained religious and redemptive content themes. While interviewees did not narrate the majority of scenes with disability centric content, one-half of the interviewees narrated disability content in their high point scenes, suggesting the positive internalization of their disability into their personal identity. The major findings confirm the importance of studying the life stories of this population from the perspective of human development theory. This study presents conclusions that impact research methodology for this population, as well as, social work research, policy development, practice and education.

KEYWORDS: mild intellectual disability, narrative, life-story,
identity-making, social work

Student's Signature

Date

IDENTITY MAKING PROCESS OF INDIVIDUALS
WITH MILD INTELLECTUAL DISABILITIES

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November 19, 2013

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Martha Nussbaum (1997) suggests that we create a “narrative imagination”, or the ability to think what it might be like to be in the shoes of a person different from oneself, to be an intelligent reader of that person’s story, and to understand the emotions and wishes and desires that someone so placed might have (pp.10-11).

My desire to understand those different from me has led me to the place of understanding how we are alike. This dissertation is a result of my childhood dream to know something different. I owe that “narrative imagination” to my sister, Kathy, who encouraged my dreams and my desire to want something more. My parents, Irene and Herb Kamlager, instilled the importance of hard work and practicality-two characteristics that have served me well.

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Chapter 1

Persons with mild intellectual disabilities constitute a significant subpopulation in the United States, and consequently a potential service population for social work. Estimates of the prevalence rate of persons with intellectual disabilities ranges from 1%-3% of the total population (Larson et al., 2001; Salvador-Carulla & Saxena, 2009; U.S. Department of Education, 2009; C. f. D. C. U.S. Department of Health and Human Services, 2006).

The overwhelming majority (approximately 87%) of people with intellectual disabilities are labeled as persons with mild mental retardation or intellectual disability. Mild mental retardation is three times more common than severe retardation (C. f. D. C. U.S. Department of Health and Human Services, 2006).

This group of persons with mild intellectual disabilities composes the faces of those who are chronically unemployed, without home ownership, ill-fitted in the community and school drop-outs. The majority of these individuals lives with their parents and rely on Supplemental Social Security Income and Social Security Disability Income (Anderson, Larson, & Wuorio, 2011; Sullivan & Adock, 1999; A. o. D. D. U.S. Department of Health and Human Services, President's Committee for People with Intellectual Disabilities, 2011). The problems facing persons with mild intellectual disabilities and their families include: societal discrimination in areas of housing, employment and social inclusion, impact all of society, in terms of government financial benefits and other supplemental benefits, including health care, housing and job training.

Definitions of Mental Retardation/Intellectual Disability

How science defines intellectual disability and its etiology provides the cultural and societal hegemonic response to addressing the needs of persons with mild intellectual disabilities. That there is not one designated definition of mental retardation reflects the ontological confusion of the concept itself. There is no consensus between the authoritative classification systems, the International Classification of Functioning, Disability +and Health (ICF) and the International Classification of Diseases (ICD), both originating from the World Health Organization and the American Association of Intellectual and Developmental

Disabilities (AAID) regarding the definition of intellectual disability. The AAIDD (2009) defines intellectual disability as originating prior to age 18 with limitations both in intellectual and functioning, which includes conceptual, social and practical skills. Measures of adaptive functioning indicate the ability to live independently; a culturally dependent concept including the physical as well as the social/cultural environment's ability and willingness to support independent living.

The ICF recognizes the interactional nature of health, environmental and social contexts in terms of 'functioning' as mentally retarded. The AAID and the ICF regard intellectual disability solely as a disability, characterized by substantial limitations in intellectual functioning and adaptive behavior (Salvador-Carulla & Saxena, 2009, p. 1799).

The ICD (10th revision), also developed by the WHO, serves as a diagnostic tool for all general epidemiological purposes. The ICD recognizes mental retardation as a health condition. Under the ICD - 10th revision, mental retardation is characterized as a condition resulting from a failure of the mind to develop completely. Four levels of mental retardation are specified in ICD: mild (IQ 50 - 69), moderate (IQ 35 - 49), severe (IQ 20 - 34), and profound (IQ below 20). The ICD-10 states that IQ should not be used as the only determining factor; rather clinical findings and adaptive behavior should also be used to determine level of intellectual functioning.

In the United States, mental retardation or intellectual disability is defined by purpose. For educational purposes, the 2004 Individuals with Disabilities Education Act (IDEA) defines mental retardation as ". . . significantly sub average general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance" (*34 Code of Federal Regulations §300.7(c)(6)*).

These different perspectives provide fodder for ill matched approaches, both theoretical and applied in terms of provision of services for individuals with mild intellectual disabilities. One perspective, the medical model, views persons with mild intellectual disabilities as a population "suffering" with a health condition. Treatment is focused on individual amelioration or prevention efforts. Another perspective, the social interactionist model, frames the problem and resultant solutions within a larger social and cultural context, examining societal barriers and prevailing societal perceptions. The social interactional approach opens the possibility of

considering individuals with mild intellectual disabilities as inherently possessing biopsychosocial developmental needs that must be considered within the larger cultural and societal environment. This etiological debate of classification has significant implications for health care, social and educational policy.

The WHO urges defining governing bodies to agree on the operational components of disease and disability from the ICD-10, ICF, and Diagnostic and Statistical Manual (Salvador-Carulla & Saxena, 2009). Emphasizing the interactional model, the WHO has spearheaded the gathering of a growing body of evidence which substantiates the advances in care models focused on community care, person centered care, home support and inclusion (Salvador-Carulla & Saxena, 2009, p. 1799).

Over the years, society and science have considered persons with mild intellectual disabilities as defective individuals, different from the ‘average American’ and interfaced with them with a focus toward ‘fixing them’. In more recent years, researchers, academicians, policy makers and practitioners employed a social interactionist perspective, specifically stigma theory, to explore the characteristics and needs of this population in an effort to provide appropriate supports. To date, this same community of scholars and practitioners has not significantly embraced their work within a human development model.

Mild Intellectual Disability

The definition of mild intellectual disability¹ is more clouded than defining other ‘levels’ of intellectual disability. For the large majority (77% to 86%) of persons labeled as mildly intellectually disabled there are no identified biomedical causes (Croen, Grether, & Selvin, 2001). From the research literature several risk factors for mild intellectual disability are identified. Those at higher risk for this condition are males, low birth weight children, products of multiple births, second or later-born children, mother with socioeconomic disadvantages, and children whose mothers were 30 or more years of age at delivery, had less than a high school education, or African American (Croen et al., 2001).

¹President Obama signed into law the change of the term “mental retardation” to “intellectual disability”, Oct. 5, 2010. The law, known as Rosa’s Law, will change the terminology used in federal health, education and labor policy.

Characteristics of Mild Intellectual Disability

Most often, for those who are mildly intellectually impaired, the labeling process begins during the school years. As preschoolers, these children may have presented with delayed milestones; however, lack of formalized testing and educational scrutiny prevents the attachment of the label intellectually impaired. Additionally the informal cultural systems of family and neighborhood may successfully absorb these youngsters in daily activities.

As students, these children may carry labels which designate them for additional educational services. However, once away from school, they may lose this identity as other or different. Findings from the Administration of Children and Families confirm that one of the most consistent elements of prevalence studies is a temporary increase in the number of people identified as having mental retardation in the years between the ages of five and twenty-one. This temporary “growth” is a result of many people becoming quite self-sufficient or ‘invisible’ to social services after age twenty-one, but who may have struggled more with traditional academics and become identified as in need of special education services (Hewitt & O’Neill, 1998).

Macmillan, Siperstein and Gresham (1996) argue that the category of mild intellectual disability should stand apart from other categories of mental retardation. They believe that mild intellectual disability is distinctively different from other categories of intellectual disability and the pervasive weaknesses of those who are mildly impaired are the abstract reasoning and problem-solving abilities rather than the general dysfunction evident in those with moderate to profound intellectual disabilities. Jenkins (1998) states that:

the statistical plotting of a normal curve of distribution for measured intelligence has probably been the single most influential factor in the definition and creation of the category of persons known as the ‘mildly mentally retarded’. Before the advent of the bell curve the category simply did not exist. (p. 17)

Problem

Research addressing the lives of persons with mild intellectual disabilities problematizes the lives of individuals from either a medical/deficit model or stigma model. In recent years, academicians and practitioners have replaced the traditional medical/deficit

paradigm with a more sociologically oriented social interactionist paradigm employing a stigma model that continues to privilege the abled over the disabled. Bolstering this stigma approach is a moral or normative imperative that stresses the promotion of a strengths-based or empowerment/rights model (Barnes, 2003; Higgins, Raskind, Goldberg, & Herman, 2002; Wigham et al., 2008).

On a practice level, this framework translates into a service delivery model that promotes self-determination through the use of person centered planning. The principles of self-determination and the practice of person centered planning rest in normative theory of promoting of choice, personal decision making and increased community participation as a citizen (Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004; McNally, 2006; C. O'Brien & O'Brien, 2000, 2002; J. O'Brien, 2004; J. O'Brien & Mount, 1991; Plachta-Elliott, Busby, & Delman, 2006; Robertson & Emerson, 2007). What is noticeably lacking in current discussion and research in this area is the exploration of the psychological human development component that each individual brings to the process.

Current Practice Using the Prevailing Stigma Model

The current practice of person-centered planning arose from the principles of normalization and social role valorization. These principals find their origin in the sociologically based deviancy and stigma theories. Deviancy theory addresses the process of how one (group) becomes labeled an outsider or nonconformist. Assuming that deviancy exists, stigma theory considers the characteristics that lead to a person (group) becoming devalued in other's eyes and the resultant impact on the individual/group. Both theories predicate themselves on the belief that social forces (legitimate or recognized authority, i.e. physicians, educational and governmental institutions) exert the right to label. Stigma theory envelops much of the disability research and literature, including the current research on person centered planning and the resultant program development.

Normalization. In 1959, Bank-Mikkelsen, Head of the Danish Mental Retardation services originated the concept of normalization (Wolfensberger, 1980a, p. 7) with Nirje, the Swedish Executive Director of the Association for Retardation, expanding this concept into principle form 1967, (Wolfensberger, 1980b). By Nirje's definition the normalization principle means

sharing a normal rhythm of the day, with privacy, activities, and mutual responsibilities; a normal rhythm of the week, with a home to live in, a school or work to go to, and leisure time with a modicum of social interaction; a normal rhythm of the year, with the changing modes and ways of life and of family and community customs as experienced in the different seasons of the year. (Nirje, 1994, pp. 32-33)

In the 1970's Wolfensberger, 'Americanized' the normalization principle to mean

the use of culturally normative means (techniques, methods, tools) to enable people's life conditions (income, housing, jobs, and recreation) to be at least as good as those of average citizens. Culturally normative is not used here to mean *the* average, *the* normal, *the* mean, but rather, in the sense of what's broadly accepted, a range of what is expectable and ordinary, where people would not raise their eyebrows to encounter. Moreover, culturally normative means would be called in to play to, as much as possible, enhance and support people's behavior, appearance, experiences, status, and reputation in their own eyes and in the eyes of others. (as cited in Yates, 1994, p.118)

Wolfensberger (1992) described the principle of normalization as a meta-theory, or meta-system.

A person becomes deviant by a) being different from others, in b) one or more dimensions of identity, which c) are viewed as significant by others, and d) this differentness must be negatively valued. It is not the differentness itself that makes for deviancy in this definition, but negatively valued differentness (p. 8).

In this statement, Wolfensberger qualifies the difference in terms of a naming power component (i.e. that someone [greater societal powers] other than the individual [entire 'deviant population'] has the defining power to attach a characteristic of good/bad or valued/nonvalued onto the person [population]).

Social role valorization. Wolfensberger (2002) defines social role valorization, the second key concept of his larger framework, as

an overarching conceptual and action scheme that informs how one may be able to enhance people's social roles if that is what one wants to do, a major theorem being that

such role value enhancement of people is extremely likely to lead to the conveyance of good things to them by others. (p. 257)

Social role valorization rests on several principles. First, social roles reflect behaviors, privileges, duties, and responsibilities that are widely understood and recognized within society. Further these social roles characterize a particular position within a social system. These social roles fall along a continuum of perceived value and occur within different domains (e.g. relationships, work, education, sports, community participation, religious, and residence related).

Wolfensberger's site of intervention and change lies not only with the individual, but equally so with society and the nondisabled. The principles of deinstitutionalization, community integration, normalization, and social role valorization all have been designed to enhance the quality of life of individuals with disabilities by including them in society. Furthermore, the aim of these efforts is to make society more accepting of individuals with disabilities (Thomas & Wolfensberger, 1994). As Parmenter (2001) noted, the principle of social valorization "placed extreme importance on the concept of 'deviant groups' gaining valued roles in society" (p. 277). This principle grounds current community inclusion efforts in disability services.

Person centered planning. Wolfensberger's ideas regarding normalization and social role valorization also laid the groundwork for the current practice of person centered planning. O'Brien and O'Brien (2002), claimed,

The first approaches to person-centered planning shared a common agenda which reflected their originator's involvement in the normalization teaching community of practice. The themes of increasing choice, avoiding de-personalizing labels and difference-making procedures, honoring the voices of the person and those who know the person best, building relationships, individualizing supports based on high expectations for the person's development, and demanding that agencies adopt new forms of service and organization to provide newly conceived supports express an agenda that each approach to person-centered planning followed in its own distinct way (p. 14).

Prevailing normative principles in disabilities services practice. Self-determination, a concept rich in personal agency and power, is an inherent right of all individuals in Western civilization. The US was born out of this belief.

The words ‘self-determination’ call upon visions and ideas of free movement, personal growth, personal choice, and independent decision-making. The fulcrum of person centered planning is that we all share the same basic needs, including autonomy and independence; individuality; love and acceptance through presence and participation within a family and community; continuous growth and learning and community status (Brost & Johnson, 1982).

Summary: problems with current practice approach. Current theoretical underpinnings for service delivery lack the depth of power for exploration and explanation of the lives of persons with intellectual disabilities. The U.S. model is based on a deviancy/stigma model, which assumes an inherent difference or dichotomy between those who are labeled intellectually disabled and those who are not. In this paradigm the interventions are targeted either toward making one ‘less disabled or deviant’, using an (micro) individualized approach or a (macro) structural approach. In the micro approach the person with intellectual disability is trained to appear or to perceive himself/herself as less deviant. In the macro approach educational efforts toward changing societal perceptions are targeted. Efforts to date are a combination of micro and macro. Research in this paradigm focuses on satisfaction of life, self-perception, self-esteem and community perceptions (Conroy, Fullerton, Brown, & Garrow, 2002; Hagner, Helm, & Butterworth, 1996; Holburn et al., 2004; Holburn & Vietze, 2002; Plachta-Elliott et al., 2006; Robertson et al., 2007; Sanderson, Thompson, & Kilbane, 2006; Wigham et al., 2008).

The second model framing current efforts and running concurrently with the deviancy model is the normative theory or rights based model. This model, more philosophical and justice oriented, offers little opportunity for rigorous research (Halle & Lowrey, 2002). Employing this model, one examines or explores the experiences of persons with intellectual disabilities using a checklist approach, (developed by agreement of socially desired human and civil rights) such as opportunities of inclusion and citizenship.

Although this second model produces the person centered planning approach and may yield the desired societal results of full citizenship; it is insufficient in terms of adequately understanding the lives of persons with intellectual disabilities. This rights based model, sociopolitical in origin and generated by systems change, does not address the biopsychosocial aspect of individuals.

Purpose of Study

The purpose of this dissertation, is to further the understanding of the process of personal identity development for individuals with mild intellectual disabilities, using a mixed methods approach. Specifically, the study will employ McAdams' work on narrative identity development using the concepts of redemption/contamination, generativity/stagnation and agency and communion as the guiding ideas to explore the life stories of adults with mild intellectual disabilities.

The underlying assumption of this dissertation significantly departs from the past and current research directed towards individuals with mild intellectual disabilities. This dissertation does not presuppose deficiency inherent in this population, as do past medical or deviancy models. Nor does it assume even an inherent 'difference' between those with mild intellectual disabilities and those who are not intellectually disabled as do more current research efforts, employing again the stigma model or normalization approaches, such as Wolfensberger's work. This dissertation frames the lives of individuals with mild intellectual disabilities within the typical/normal human development model, with the assumption that the stories of their lives are not cemented together by their disability but rather in those identity making events which all humans experience.

Findings from this research may add a new dimension to the overall theoretical knowledge base of narrative identity development. To date there has been little research using McAdams' life story narrative approach to understand the lives the persons with intellectual disabilities. This research will move the current state of knowledge from normative understanding to a critical exploration of the biopsychosocial development of persons with intellectual disabilities.

This research will provide a theoretical application of human development which, in turn, offers a sound theoretical underpinning to development or validation of current best practice in the field of disability services. This research will increase the understanding of the process of identity development and its application to social work to empower persons with intellectual disabilities around issues of positive identity development. This research may add to the theoretical framework of understanding and subsequently the development of and delivery of services to this population.

Lastly, this dissertation aims to offer best practice in the use of research methodologies for persons with intellectual disabilities.

Need for the Study

To best serve individuals with mild intellectual disabilities living in this time of self-determination, it becomes crucial for researchers and practitioners to understand the psychological components related to the identity making process for persons with intellectual disabilities. The normative theory or rights based principles behind current practice in disability services, such as, person centered planning, does not provide sufficient explanation to understand the powerful factors behind self-determination. The current state of research and practice rests on a stigma/deviancy framework which continues to relegate persons with intellectual disabilities to an 'other' or deficit role from the nondisabled population.

One cannot have sound practice without sound theory. There is a compelling need to add an empirically based theoretical foundation to current practice approaches with persons with intellectual disabilities. The current practice approach focuses on quantifying outcomes and making necessary organizational structural changes rather than exploring the individual's personological characteristics as they impact or are affected by the person centered planning approach.

Human development theory does not drive nor inform current approaches. An understanding of social policy forces recognizes that social policy, funding, and program development often change due to political and social/cultural priorities rather than new empirical research.

An informed service approach requires that we know as much as possible about the human psychological elements of the individual with a mild intellectual disability. One approach to understanding is exploring the process of identity making. Such a personological approach will add an essential component to disability services policy and program development.

The theoretical approach, incorporating a human development model and specifically, a life story narrative framework used here is one based on the process of identity making. Personological or human development theory is missing from this largely sociological understanding and resultant solution to raising the image and acceptance of persons with intellectual disabilities in society. However, the basic assumption of normalization or social role

valorization that each person is valuable and contributes to society in an individualized manner fits well with the human development concepts of personal agency and communion (Wolfensberger, 1980a, 2000).

Equally significant to the application of theory to understand, generate, and eventually evaluate practice, is the research contribution to the fields of human development/narrative identity theory and disability studies. To date, the application of human development identity or life story narrative theory to the understanding of identity making process for persons with intellectual disabilities is missing. The core researchers in life story narrative or identity theory (Josselson, Lieblich, & McAdams, 2003; McAdams, 1993, 1996, 2001, 2006a, 2006b; McAdams & Bowman, 2001; McAdams & de St. Aubin, 1992) have not explored such processes with this population. In personal communication, McAdams (2009b) acknowledged this research gap and encouraged efforts to use his concepts to explore the life stories of persons with intellectual disabilities.

In disability studies, the overwhelming body of research is framed either in structural paradigm of oppression and discrimination or a social interactionism paradigm of stigma and deviancy. The 'politics of disability' has overshadowed the elemental human development approach of understanding narrative identity. By continuing to focus on the disability, whether from a stigma or deviancy approach or an oppression/minority framework, we have lost the common elements of personhood.

Theoretical and Empirical Research for Persons with Mild Intellectual Disability

Since the 1960's researchers have explored the concept of social identity for individuals with intellectual disabilities. The majority of research positions itself in the stigma paradigm and considers the external collective or social factors in identity making rather than the personal or self identity processes. Lee and Hobson (1998) echo this concern for lack of systematic research on the self-conceptions of children, youth and adults with intellectual disabilities (p. 1132). The research lacks depth in its exploration of the psychological dimensions of persons with intellectual disabilities and identity making.

Past and current empirical research explores factors such as: to what capacity a person internalizes disdain/stigma, the relevance of friendship networks on identity making, ethnicity identity compared to disability identity, incompetence and identity, the yearning for social

recognition, unmet sexual needs, institutional vs. community perceptions of identity and social comparisons between siblings (Angrosino, 1992, 1994, 1997; Appleton et al., 1994; Beart, 2005; Craig, Craig, Withers, Hatton, & Limb, 2002; Cunningham & Glenn, 2004; Cuskelly & deJong, 1996; Dagnan & Sandhu, 1999; Epp, 2003; Flynn & Knussen, 1986; Gibbons, 1985a, 1985b; Goodley, 1998; Jones, 1992; Kennann, 1984; Koegel, 1986; Koegel & Edgerton, 1982; Korbin, 1986; Langness, 1994; Langness & Levine, 1986; Raymond, 2000; Reiss & Benson, 1984; Sandvin, 2003; Schurr, Joiner, & Towne, 1970; Seale, 2001; S. J. Taylor, 2000; Todd, 1995; Whitmore, Langness, & Koegel, 1986; Zeitlin & Turner, 1984).

It is crucial to reiterate that the disability studies field lacks research exploring the human development psychological process of identity making, outside of the parameters of stigma. The majority of research either agrees with the stigma assumptions or reacts against it, both continuing to operate from those assumptions. It is clear that there is an additional significant need to understand the complexities of individuals with intellectual disabilities without attempting to prove or disprove that stigma or deviancy is a key factor in an individual's identity.

Empirical research approach focuses on quantifying outcomes and making necessary organizational structural changes rather than exploring the individual's personological characteristics as they impact or are affected by the person centered planning approach.

What is missing, in this current drive toward increased self-determination, is understanding the phenomenological nature of each person as it relates to the identity making process. As researchers we can listen to and understand these stories of individuals who value and participate in self-determination actions, such as person centered planning, with the theoretical 'ears' of the life stories narrative approach. Such an approach offers insight into understanding the developmental processes that lead to a rich, satisfying, generative life or conversely that lead to a stagnant life.

This research fills this gap in understanding persons with mild intellectual disabilities from a life story narrative approach using the lens of human development.

Identity Theory

As stated earlier, the overwhelming bulk of research in the field of disability studies neglects work in human development theory, specifically the developmental area of identity and/or identity making process. For millennium, scholars and philosophers have pondered the

questions *what is human identity?* and *how does it come into being?* It is not the intent of this research to engage in this argument but rather to confine itself to a definition that is conceptually sound and applicable for the purpose of this research. As Rummens (2003a) observes, “(T)he very way we conceptualize a social phenomenon informs the identification of relevant issues and the formulation of related research questions” (p. 3). For purposes of this research, identity is defined as “the distinctive character belonging to any given individual, or shared by all members of a particular social category” (Rummens, 2003a, p. 4).

Rummens (2003a) discusses identity using a multi-dimensional approach. She considers identity as consisting of three relational types: a personal identity, social identity, and ego identity. Cote and Levine (2002) consider the relationships of these entities as iterative, interactional, and subjective. Rummens (2003a) also makes conceptual distinctions between the processes of identity formation or development, identity construction and identity negotiation. (Rummens, 2000) considers the parts of identity as being both relational and contextual; whereas the act of identification is best viewed as inherently process driven. Adding the dimension of change over time places these concepts in interactional, overlapping, and active states. Figure 1.1 located at the end of this chapter illustrates how this research fits into Rummens’ multi-dimensional approach to identity. Similar to many identity theorists, Rummens situates her work in Erikson’s ideas that identity is largely determined by the contextual dimensions.

Identity Processes

The formation or development of an identity incorporates social, personal and ego identity. Based in post-modern identity research, Rummens regards individuals as possessing multiple selves; there is a plurality of identities, operating at any one time, and dependent on the situational context, historical time and cultural context.

Identity formation/development. My research explores identity formation. Identity formation addresses the question how do I fit in the world? Primarily, this identity formation process is a cognitive developmental process that each person undergoes as part of his/her maturational process. The body of research literature focused on identity formation explores the links between identity development, self-confidence, self-competency, and personal, collective, group or global self-esteem. It also investigates the impact of individuals’ sense of attachment, sense of belonging, and sense of commitment; and considers the effects on personality on

psychological and psychosocial adjustment, as well as on mental health and well being (Rummens, 2003b).

Identity construction. The second process, identity construction, refers to the “creation, formulation, and expression of personal and/or social identities for the self, either by individuals or groups” (Rummens, 2000 as cited in Rummens, 2003, p. 7). Focus in this process is on the creation of collective group identity and the cultural influences on this collective identity construction. Researchers investigate the social construction of identity through language, cultural identity markers and opposition to collective identities (Rummens, 2003b).

Identity negotiation. The third process, identity negotiation, largely sociological in nature, “refers to the political nature of personal and social identification of self/and or other, between or among, and by or within groups, via the interactions of individuals” (Rummens, 2000as cited in Rummens, 2003, p. 7). Group consciousness and its impact on social identity are examined in this process.

Summary: identity processes. Each process recognizes the significant influence of social factors in the formation, construction or negotiation of identity. Identity is a process that incorporates the social construction of self with the psychological human developmental needs. A significant portion of disability research falls into the categories of identity construction and identity negotiation.

Identity Types

Personal identity. My research focus fits into the exploration of personal identity. Rummens (2003b) defines personal identity as “self-identification on the part of the individual... Personal identity is the dialogical intersection of social and psychological spaces” (p.19).

Social identity. In contrast to personal identity, social identity “is the outcome of an identification of self by others. It is identification accorded or assigned an individual by another social actor” (Rummens, 2003b, p. 19). Social identity, which has a second tier component of collective identity, connects to social structure, role-anchoring, social embeddedness, attachment and a sense of interdependence. Examination of perception of social roles occurs in social identity. To date, the majority of research on identity and persons with disabilities takes place in the social identity.

Ego/self-identity. Rummens distinguishes personal identity and social identity from the notion of ego or self-identity.

Self-identity concerns itself with the state of being a unique person distinct from all others as reflexively understood by that individual through time, and has been largely the domain of psychology. Personal identity and social identity focus instead on the social comparisons and positioning of individual and groups within society... Self-identification processes do not occur in a vacuum but are rather influenced by...social identifications (p. 8).

Erik Erikson's influence is evident in the work cited above. Erikson's life work focused on conceptualizing identity and personal self-hood, terms, at times, used interchangeably. For Erikson (1980), personal identity is differentiated from ego identity. The personal identity is "based on one's immediate perception of one's selfsameness and continuity in time and the simultaneous perception of the fact that others recognize one's sameness and continuity" (p. 22). Ego identity includes a sense of future within a collective social reality and addresses the question of How do I fit? (Erikson, 1980, p. 22).

Summary: identity types. There are many approaches to understanding identity. The approach of this research considers identity not as a "product" but rather as an ongoing process that continues throughout one's life. The process explored here is that of identity formation. Identity formation occurs within a cognitive developmental framework and answers the question how do I fit in the world?

Unlike most research in the disabilities field, the focus of this research is personal identity. The interrogation of personal identity is compatible with the research emphasis on understanding the individual experience with a developmental framework rather than a stigma or deviance framework.

Life Story Narrative Identity

Also compatible with Rummens' delineation of identity by process and by type is the life story narrative approach or framework. (McAdams, 1993, 1996, 2001, 2006a; McAdams & Bowman, 2001; McAdams, Josselson, & Lieblich, 2001, 2006) According to McAdams (2001), identity is the internalized and evolving stories that we tell about ourselves that weave together the reconstructed past, the perceived present and the anticipated future in an attempt to provide

one's life with unity and purpose. For McAdams, identity is the core organizer of the life story - so much so that he suggests they are one and the same. Using Rummens' categorizations, narrative identity fits into the process of identity development. The development of a narrative identity follows the psychological developmental path of *where and how do I fit into the world*. The development or formation of a personal identity marks the work of McAdams and other narrative identity theorists (Geertz, 1974; Gergen & Gergen, 1986; Josselson, 2003; Kleinman, 1995; Mishler, 1986a; Polkinghome, 1988; S. Rubin et al., 2001; Singer, 2004). Narrative identity theorists consider the modality of the life story essential to the understanding of power and intimacy, and ultimately for the understanding of the process of developing identity.

Key to McAdams' thinking is that life is purpose driven (2001). The development of the purpose is continuous and is a result of our remembered past, perceived present, and anticipated future. McAdams provides a chronological road map to the making of the personal identity. He incorporates a variety of theoretical concepts from prevailing research; primary among these are the works of Kohut, Piaget, and Erikson, to develop his own trajectory of individual development (McAdams, 1993).

McAdams' empirical research and subsequent theorizing on the concepts of communion, agency, generativity, redemption, and contamination related to the process of identity formation, prove useful to my research interest. McAdams' concepts give one a conceptual picture or guide to viewing identity formation as an ongoing process. In particular his most recent research using the life story approach (McAdams, 2006b) on generativity, redemptive, and contamination stories of middle age and older psychologically healthy adults opens up or extends the exploration of the active psychological developmental process of identity making.

McAdams' Key Concepts

Redemption and Contamination

The concepts of redemption and contamination offer descriptions to understand the overall or predominant story of one's life. McAdams (2001, 2006a; McAdams & Bowman, 2001) discusses this in terms of a story or script mechanism. Redemption stories are those with bad beginnings or scenes but redeemed by a positive outcome. There is an emotional movement from a negative narrative to positive tone. Redemptive stories echo personal transformation and improvement. Gergen's and Gergen's (1986) work concurs that during redemptive sequences

there is the likelihood that one undergoes an increased understanding of the self. A typical statement in a redemptive sequence is, “it was very difficult but it helped me to be stronger in my lifetime”. McAdams (2006b) employs a typology of redemptive stories as atonement, emancipation, recovery, enlightenment, development, and upward mobility. In narrative terms one talks of a story and how the protagonist struggles to overcome obstacles.

The contamination story is the counterpart to redemption. The ‘action’ or feeling moves from good to bad. An emotionally positive experience turns sour or is ruined by a bad outcome. A typical statement in a contamination sequence is, “it’s difficult for me to overcome”. Contamination sequences expose fatalism and oftentimes a fixation on the past (McAdams, 2001, 2006b; McAdams & Bowman, 2001).

McAdams acknowledges that everyone has stories of each type; however, there is a pattern that recurs during times of transitions or life-narrative turning points. This pattern can be categorized as either redemptive or contaminated.

Generativity and Stagnation

Using Erikson’s developmental terms of generativity and stagnation, McAdams ties these concepts to the broader identity story of redemption or contamination. McAdams situates the origin for generativity as

designed by evolution to act and feel in certain ways, that when filtered through culture, function to promote the growth and well-being of future generations...It is therefore, both natural and good today as it was in the Environment of Evolutionary Adaptedness (EEA). (McAdams & Pals, 2006, p. 49)

The need for generativity is universal and consequently part of the narrative of the life story. Generativity is understood as the concern for and commitment to promoting the well-being of later generations (McAdams & Bowman, 2001). Developmentally, adults search for meaning through their commitment and contribution to future generations. According to McAdams, earlier experiences (remembered past) provide the quality of that human faith and the direction of the quest. It is during adulthood, that individuals, through the generativity script, link “to the collective stories and myths of society as a whole and to the enterprise of promoting and improving human life and welfare from generation to another” (p. 14). Conversely, stagnation is

the result of not feeling creative, not feeling connected to the future; one feels rejected and is rejecting.

Agency and Communion

McAdams subscribes to the belief that human life is based on two central psychological motivations, power and love (McAdams, 1993, p. 68). These motives prompt the person to act in characteristic ways. McAdams finds agreement in Bakan's (1966) concepts of agency and communion, aligning them to power and love.

Agency refers to the individual's striving to separate from others, to master the environment, to assert, to protect and to expand the self. Autonomy, power, competency, and achievement are descriptors for the concept. Agency may also be considered as one's belief system of independence. Behaviorally or by report, one accounts for agency, for example, in choice making, goal setting, goal accomplishment, and perceived freedom.

Communion emphasizes human ties and relationships. It is a desire to participate in something that is larger than the self - in a warm, close and intimate manner. One describes communion in terms of affiliations, relationships and nurturance. Behaviorally, or by report, one accounts for communion, for example, in levels, intensity and quality of participation with others.

McAdams, et. al. (Grossbaum & Bates, 2002; McAdams & de St. Aubin, 1992) considers agency and communion in terms of motivational or behavioral concepts. Motivations are identified within ego, personal and social identities. Behaviors are witnessed in the personal and social identities. According to McAdams (1993), one finds the themes of agency and communion in the character's recurrent actions or intentions, evidenced in the narrative. These themes begin in elementary school years and become part of the internal disposition (p. 73). As yet there are not themes but motives. During adolescence an internal struggle ensues as a result of the incongruities of the two motives. Multiple selves represent/embody each motive. This is the beginning of identity, the incorporation of multiple selves, or as McAdams names it, the first draft of life stories. These are fables more so than stories during this developmental period.

An equally significant conceptual intersection is that of generativity and agency and communion. During the adult generative stage, the need for and expression of agency and communion move closer together. The measuring stick of one's life is reflected in both agency

and communion and often the valued life experiences merge the two dimensions. Individuals reflecting on their lives consider success or quality in terms of both personal agency or individuation and positive intimate relationships.

Relationships Between Key Concepts: Generativity/Stagnation, Redemption/Contamination and Agency/Communion

Relationship between Generativity/Stagnation and Redemption/Contamination

Empirical research finds that “adults who are strongly committed to providing care for and making significant contributions to future generations - tend to construct life stories that feature many redemption sequences compared to less generative adults” (McAdams & Bowman, 2001, p. 18). Furthermore, “a narrative identity that celebrates redemption may provide a solid platform from which to launch generative projects and endeavors” (p. 18).

The perception of one’s life as being redemptive or generative has profound implications for one’s ability to adapt to everyday stresses and crisis and to overall mental health. Gergen and Gergen (1986) employ the narrative device of redemption sequences when charting the upward movement from negative to positive, and one’s progressive understanding of the self as moving forward over time.

Relationship between Generativity/Stagnation and Agency/Communion

Empirical research in this area finds that “(a)adults high in generativity have broader friendship networks and perceive that they are closely tied to other people in their communities, compared to adults low in generativity” (Hart, McAdams, Hirsch, & Bauer, 2001 cited in McAdams, 2006b, p. 57). McAdams (2006b) cites research support for his findings on generativity from several studies (Booth & Booth, 1996; Hart et al., 2001; Peterson, 2002; Peterson & Klohnen, 1995; Peterson, Smirles, & Wentworth, 1997; Rossi, 2001). Research findings include that adults high in generativity have high participation rates in religious, political, and civic venues compared to those lower in generativity. There is a more committed sense of social responsibility for adults high in generativity compared to those lower in generativity (Pratt, Norris, Arnold, & Filyer, 1999). Additionally, research suggests that highly generative adults report higher levels of happiness and life satisfaction and lower levels of depression and anxiety, compared to less generative adults (Ackerman & Zuroff, 2000; de St. Aubin & McAdams, 1995; Grossbaum & Bates, 2002; Keyes & Ryff, 1998; McAdams, Hart, &

Maruna, 1998; Snarey, 1993; Stewart & Vandewater, 1998; Vaillant, 1977; Vandewater, Ostrove, & Stewart, 1997). Highly generative adults express strong, unconscious, needs for both power and intimacy (Ackerman & Zuroff, 2000; de St. Aubin & McAdams, 1995; McAdams, Ruetzel, & Foley, 1986; Peterson & Stewart, 1993; Rossi, 2001, as cited in McAdams, 2006a, p. 57) . In sum, “the empirical research suggests that generativity is good for others and good for the self” (McAdams, 2006a, p. 57).

Application of Life Story to Persons with Mild Intellectual Disability

For the researcher who tries not to assume stigma as the predominant influence in the life stories of persons with mild intellectual disabilities, the condition of disability is relevant only if the disabling condition or lack of appropriate supports/accommodations complicates the fulfillment of the developmental needs of generativity, power, and love. Concurring with O’Byrne (2000), understanding what the story is about for individuals with intellectual disabilities requires giving up the single vision of what it means to be a person with a disability. These individuals are not the construct that society places on them. However, aware of the obvious societal discrimination which occurs daily for persons with intellectual disabilities the researcher would be remiss not to consider the potential impact on one’s personal identity formation.

McAdams’ (2006b) faced a similar research challenge in 1994 when he undertook the first major study of generativity among African American and Euro-American adults. He notes that prior to this study that researchers’ inquiries were often premised on the assumption that minority groups in the United States are disadvantaged or deprived in some manner - showing lower levels of achievement, higher levels of delinquency, more social problems and so on. Very few psychological studies have examined the lives of African American adults, and fewer still have examined positive aspects of those lives, such as leadership, altruism, generativity, and so on (p. 178).

In this study, two hundred fifty-three adults between the ages of 35-65, split approximately equally between African American and Euro-American, were sampled. Seventy-four participants, those who scored either especially high or especially low on the measures of generativity, were called back for in-depth life story interviews.

For both Blacks and Whites, individual differences in generativity proved to be significant predictors of mental health and constructive social involvement. For both Blacks and Whites, generativity was positively associated with self-report measures of life satisfaction, self-esteem, and life coherence, and negatively associated with depression (p. 178).

From the study's results, McAdams suggests two ideas about generativity and race in America.

First individual differences in generativity are associated with the same kinds of behaviors for both Blacks and Whites. ...Whether you are African American or White, the data suggest, generativity brings the same personal and social benefits. Second, African American adults tend on the average to show slightly higher levels of generativity overall as well as higher levels of social support, religiosity, and the study's measure of generative parenting, compared to White adults. (pp. 179-180)

McAdams attempted in this study on generativity "to emphasize the strengths and adaptive resources of African American adults and the resilience of Black families" (p. 180). He found that, despite lacking of advantages that many White Americans enjoy, African Americans showed no deficiencies whatsoever, in the "very important psychological resources in adulthood-generativity" (p. 180), and "...may have even scored slightly higher than their White counterparts" (p. 180).

Although my research is not focused on African Americans, a similar quest is pursued in my research; my focus is to explore and uncover the themes of redemption/contamination, generativity/stagnation, agency, and communion in a population that most often is perceived as deficient.

Study Framework

One can consider this Study Framework section as the researcher's contract on the conditions and execution of the study. What will the research produce and under what conditions will the study occur? This study centers on the exploration of the identity making process of individuals with intellectual disabilities. McAdams' considers identity as the core organizer of the life story. Identity, it has been argued, is what makes us human. However, this self is not essentialist. There are many parts or selves to the composite identity. In this research the process of personal identity development is explored. Personal identity is self-identification

in contrast to a social identity. Self-identity or personal identity is what makes one unique distinct from all others.

To understand this process, McAdams' life story narrative approach conceptually frames this study. Within this approach are the following assumptions: 1) Every person moves through life with two powerful motivations pushing them, power (agency) and love (communion). How these motivations are acted upon is contextualized to one's time, place, situations and social roles. 2) It is a unique process of how each individual develops an identity and a life story. 3) This individual narrative may be conceptualized in terms of a redemptive or contaminated story that has prevailing elements of generativity or stagnation, agency or communion. The typology of redemptive stories include atonement, emancipation, recovery, enlightenment, development, and upward mobility. 4) There is a solid history of empirical research using the above concepts.

This research has progressed to not only analyzing the individual life stories to exploring and understanding themes and patterns present in persons who can be described as living a redemptive or contaminated story, as being generative or stagnant or as possessing and acting upon agentic or communion motives. Current research completed with samples of persons without disabilities show strong relationships between redemptive stories and positive mental health factors, high generativity and redemptive stories. A strong sense of agency and communion, considered two powerful psychological motivators, are evidenced in life stories of highly generative persons. Table 1.1 located at the end of this chapter provides a simplified visual of the above discussion. Figure 1.2 offers a process model for the understanding the conceptual model.

Using a sample of twelve persons who are grouped by higher or lower generativity, this research searches for such themes and relationships in the lives of persons with intellectual disabilities. The research employs a mixed methods approach, increasing the validity of the study, extending the scope and depth of the understanding regarding the data and/or elaboration or development of analysis.

Research Questions

1. What experiences influence the formation of identity for sampled persons with mild intellectual disabilities?
2. What are the common themes that offer insight into the developmental processes that lead to

- a) Communion
 - b) Agency
3. Are there similar and different response patterns of communion and agency within the sample?
 4. What are the common themes that offer insight into the developmental processes that lead to a
 - a) Redemptive Narrative Story
 - b) Contaminated Narrative Story
 5. Are there similar and different response patterns of redemptive and contaminated narrative story within the sample?
 6. How do the narrative themes of generativity and stagnation show themselves?
 7. Are there similar and different response patterns of the themes of generativity and stagnation within the sample?
 8. Are there other contributing factors in the identity making process that are not described by the communion, agency, or generativity?
 9. What is the influence, if any, of disability in the experiences of the sampled persons?

Summary

Chapter 1 presented evidence for understanding the lives of persons with mild intellectual disabilities using a narrative life story approach. The prevailing assumption in research with this population directs research and subsequently practice to prioritize the ‘disability identity’ rather than the human identity. Current disability services practice also operates from a normative base of promoting self-determination rather than recognizing human developmental needs of communion and agency, which results in programs promoting self-determination and community inclusion. Following the argument for a different theoretical approach, concepts key to understanding the life story approach and identity theory were presented.

In the following chapter a review of the literature is presented. The literature review focuses on relevant research and theoretical models originating from the disability studies field and literature addressing the conceptual narrative life story model.

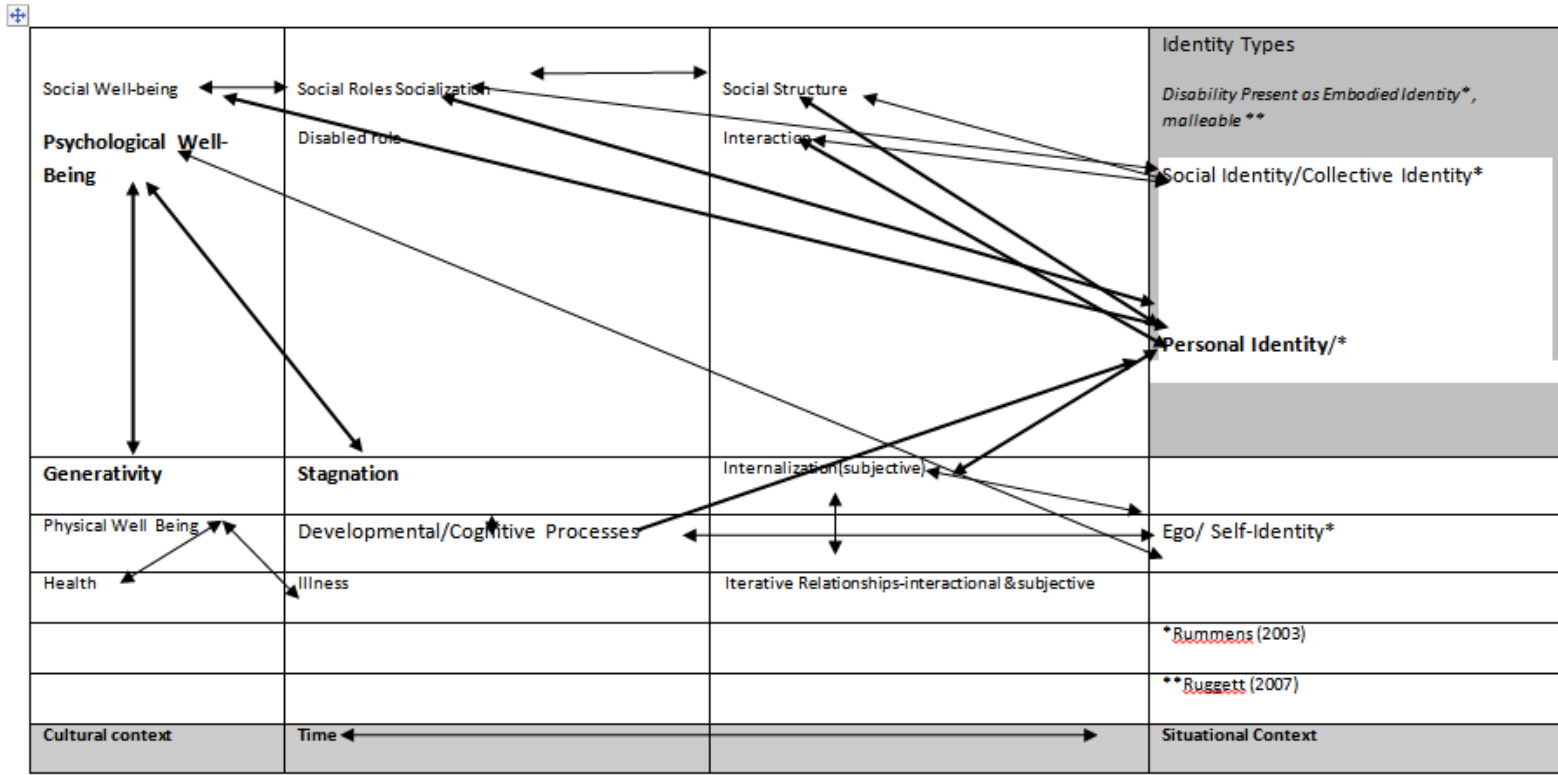
Figure 1.1 Dissertation Research Organized within Rummens' Multi-dimensional Approach to Identity

Identity Processes	Identity Types	Identity As a Whole
<p>Identity Formation/Development How do I fit in the world?" Cognitive developmental process Focus of this research</p>	<p>Personal Identity Self Identification Focus of this research</p>	<p>Identity-Narrative Life Story Identity is the internalized and evolving stories of the reconstructed past, the perceived present and the anticipated future (McAdams) Focus of this research</p>
<p>Identity Construction Creation of collective Identity Typical research on disability</p>	<p>Social Identity Collective Identity Typical research on Disability</p>	
<p>Identity Negotiation Political nature of personal and social identification of self and or other Typical research on disability</p>	<p>Ego or Self/Identity State of being a unique person distinct from all others; sense of future within a collective</p>	

Table 1.1 Overall Life Story Narrative Understood by the Constructs of Agency and Communion

Agency	Communion
Motivations	Motivations
Autonomy	Affiliation/Nurturance
Power	Need for intimacy/relationships
Competency	
Behaviors	Behaviors
Accomplishments	Social Network Participation
Choice Making	Strength, intensity and quality of relationships
Goal setting	
Perceived Freedom	

Figure 1.2 Construction of Life Story Narrative of Persons with Intellectual Disabilities Key Factors and Concepts in Identity



Lines doublebolded are primary focus of proposed research.

Chapter 2

Chapter 2 discusses the literature relevant to this research. To comprehensively address the literature review this chapter is organized in the following manner. First discussed is relevant disability centered empirical and theoretical literature. A heuristic device to frame the literature review for theoretical and empirical research on intellectual disability and identity is presented.

This is followed by review of the conceptual framework focused on the human development model, the identity making process and the life story approach. Accompanying tables at the end of this chapter offer another organizational tool for understanding this material.

A more detailed discussion is offered regarding Wolfensberger's model of normalization and social valorization as it immediately foregrounds current practice thinking. This disability related focus is then followed by an extended review of McAdams' the conceptual framework of identity making, including McAdams and Pals (2006) theory of the five principles of personality theories. A review of Rummens' ideas regarding the processes of identity making and identity types and a discussion of McAdams' concepts relevant to this research follows. The chapter ends with a restatement of the research questions.

Paradigm Approach to Conceptualizing Intellectual Disability and Identity Making Process

This research applies the framework of the theoretical paradigms of positivism, structural determinism (post-structuralism), social interactionism/constructionism, and phenomenologism to conceptualize disability. Watson (2002) presenting an extensive theoretical overview of sociological issues related to identity and disability, in general, postulates two main schools of thought, social interactionism and structural determinism. These worldviews locate the conversation of how one perceives reality, what are the perceived problems from this view, and what are the sites of and treatment/intervention for this problem.²

As Williams (2001) states,

² This author acknowledges the work of Dr. Dale Albers in framing the creation and understanding of knowledge within the paradigms of social interactionism, existentialism, positivism and structural determinism.

Disability is something-if it actually is anything at all- that is framed in a number of different ways with very different implications for our knowledge, policies and practices ... (T)he terrain is multi-paradigmatic and the development of relationships between different paradigms need to be seen in a historical context (Oliver, 1996) if the analyses is to avoid the kind of standoff across a divide that boldly needs bridging (Barnes & Mercer, 1996) (pp. 127-129).

The Paradigm Approach

Early research framed understanding of disability related issues within the medical or positivism model. This worldview in which research was conducted was replaced by thinking in the social interactionism or structural determinism paradigms. More current thinking and research posits the question of the identity making process within a poststructuralist framework.

Of note is that the majority of discourse in the area of disability occurs within the academy of disability studies and speaks from a sociological perspective rather than a human development or psychological perspective. The following review of the literature highlights the differences of paradigms between both theoretical discourse and empirical research.

Paradigms

Social Interactionism/Social Constructionism

From the social interactionism/social constructionism paradigm one considers mental retardation as “a socially situated concept steeped in moral and cultural values” (Bogdan, 1982,p.5). Bogdan, operating from the social interactionism paradigm, questions the scientific community’s assertion that there exists a “true or “fixed” definition of mental retardation and he concludes that “(M)ental retardation exists in the minds of those who use it as a term to describe cognitive states of other people” (p. 7). Trent, (1994) offering an extensive history of the making of mental retardation, in *Inventing the Feeble Mind*, considers the definition within a more contextual view appreciating the historical conditions and relativity of knowledge. He regards mental retardation as “a construct whose changing meaning is shaped both by individuals who initiate and administer policies, programs and practices and by the social text to which these individuals are responding” (p.2). Rapley (2004) agrees that “what is to count as (in)competence is negotiated and constructed locally, and for local purposes, by local means” (p. 202).

Turner (2001) describes social interactionism/constructionism as “probably best regarded as a historical and sociological account of how certain conditions (disease, sickness, impairment or disability) become accepted over time by the medical professional and the wider society and how that historical process is shaped by political struggles and economical interests” . Watson (2002) conceptualizes this approach to identity making as “a self that is created through knowledge about the self build up from others’ opinions of the individual...” (p. 513). The primary assumption of social interactionism is that disability is a social construct situated in a historical context. Jahoda, Markova and Cattermole (1989) state that “at the present the most commonly adopted approach to the study of self is based on social construction theory” (p. 104). According to the more recent work in this paradigm identity is fluid across time and space and contextual in nature. Research from this perspective examines the context and the construction of disabling experiences.

Stigma/deviance perspective. The particular lens of stigma or deviancy is used within the larger paradigm of social interactionism. Within the traditional stigma paradigm, disability is a deficit and persons with disabilities struggle to reconcile this inherent deficit with their sense of identity. This internalized sense of deficiency or stigma is a social production created by the interactions between persons with disabilities and others. A prevailing assumption of the stigma research is the lack of agency on the part of the “stigmatized” person. Typically, the studied population is regarded as a vessel to receive the stigma message and the research merely reports on the effects of receiving such messages.

There is a minority of researchers, operating in the social constructionism paradigm, who do consider the concept of agency as crucial to identity making and self-concept for persons with intellectual disabilities (Jahoda & Markova, 2004; Jahoda et al., 1989). Contrary to the traditional stigma assumption of passivity, these scholars explore agency as a key factor in self-concept and the internal process of challenging social norms. “The disability movement and evolving theories of self, now point to individuals’ ability to develop positive identities

and to challenge stigmatizing views and social norms” (Jahoda et al., 1989,p.719).³

Structural Determinism/Poststructuralism

More recent researchers frame their work within the minority/oppression or structural determinist paradigm-(Barnes, 2003; Baron, Riddell, & Wilson, 1999; Chappel, 1996; Chappell, Goodley, & Lawthorn, 2001; Crow, 1996; Epp, 2003; Field & Hoffman, 1997; French & Depoy, 1997, 2004; Gill, 1997; Hahn, 1995, 1997; Marks, 2002; Oliver, 1996; Rapley, 2004; Rapley, Kiernan, & Antaki, 1998; Riddell, Baron, & Wilson, 2001; Watson, 2002; Zola, 1993). This wave of research likely reflects a reaction to past stigma research. The minority model may reflect the political use of research in righting those wrongs of previous research while also reflecting the more participatory approach in research methodology.

For example, in a poststructuralist worldview paradigm, Foucault (1965) asserts that the diagnosis of mental retardation results from persons unable to meet societal expectations about self-sufficiency and normative expectations.

The center of Foucault’s work is the body, which he regards as the object of knowledge and the target for the exercise of power. The body is now the site of meaning and becomes consequently the site of resistance. Theoreticians in this paradigm frequently elaborate on the power of the name (i.e. disability, mental retardation) and its penetration of the flesh (body) or self-identity. Impairment is viewed as a product of discursive practice, rather than an original, a performance rather than an essence. (J. Butler, 1990) The identity of intellectual disability is a master category and the struggle is to reclaim that identity into a resistant group identity. In this paradigm, the concepts of agency and identity-making operate within a power structure of competing and contextualized identities. The self is multiple and is not essential it changes as the context changes. Scholars ask “to what extent are people involved in the voluntary construction of social identity and to what extent are their lives shaped by social structures of gender, race,

³ In contrast, outside the disability research the concept of agency and its relation to self and collective humanity is considered significant to identity development (Cote & Levine, 2002; Geertz, 1973; Kleinman, 1988; C. Taylor, 1989). This absence in the disability research of a key concept that prioritizes an individual’s humanity (agency) speaks to the cultural and research assumptions that agency is not proscribed to persons with intellectual disabilities. This nonrecognition of personal agency and its contribution to the process of identity making highlights a research need.

disability and social class?” Agency, a key issue in identity analysis, is framed within the power-based concept of self-determination (Baron et al., 1999; Epp, 2003; Field & Hoffman, 1997; Jenkins, 1998; Riddell et al., 2001; S. Rubin et al., 2001; S. Rubin & Heal, 1996; Watson, 2002).

The structural determinist paradigm also contains theories of human development psychology. In the field of disability research there is little theoretical discussion about this approach. The empirical studies, which are discussed later, focus on theories of sequential adjustment stages to acceptance of disability.

Research from this perspective examines disability with an underlying assumption that definitions are socially manipulated by a power structure and that this power structure does not include those who are being defined.

Positivism

From a positivist paradigmatic view, the cognitive nature of the disability is emphasized (Jensen, 1980). Jensen refers to mental retardation as the “thinking disability” and that a single set of expectations and norms could be applied to this condition (as cited in Parmenter, 2001, p. 281). The diagnostic medical definitions of mental retardation/intellectual disabilities addressed in Chapter 1 appear to reify the notion that mental retardation is an ‘it’, a singular or essentialist entity, fixed as a result of internal and mental attributes. The ‘it’ is discovered as an outcome of “scientific” biopsychometric testing proving a pathological root. Within the positivist model, frequently referred to as the medical model, there is a presumed biological reality of impairment. The illness and subsequent point of intervention is situated in the body. Using standardized tools, professionals assess a person for generalized functional capacity, assuming a universal definition and measure of dysfunction. Measures of health, well-being, and quality of life are driven by universality and generalizability. (Williams, 2001). Identity development is a result of deficits in ‘normal’ development, and disability is considered a maladjustment from the normal or typical (Schurr et al., 1970).

Phenomenologism

Disability academicians operating from the phenomenological perspective consider the body and mind as inseparable, and that humans are grounded in the relationship between embodiment and the world; a notion taken from Merleau-Ponty (as cited in Turner, 2001). A significant number of narratives centered on persons with physical disabilities employ this

approach through the interpretation of the subjective experience of the “lived body” (Paterson & Hughes, 1999). Within this framework the “being” of mental retardation is a personal experience that is not generalizable. Research methodology within this framework emphasizes a grounded theory approach with participatory or emancipatory collaboration with the “subject” (Knox & Hickson, 2001; Knox, Mok, & Parmenter, 2000).

Counterarguments Across Paradigms

A counterargument to the positivist approach is that disability is not an essential entity but that it is fluid and changes by situation. Rapley (2004) observes that the identification as intellectually disabled is a “social judgment consequent upon the enactment of certain social processes mediated by certain specific bodies of knowledge” (p.42). Those in the social interactionist and poststructuralist paradigms argue that the positivists treat stigma as a static behavior rather than dynamic and interactional (Parmenter, 2001). Proponents of social interactionism criticize the structural determinists as having “little room... for an understanding of how identity forms, how selves are constructed by others and construct themselves” (Dunn, 1998 as quoted in Watson, 2002, p. 510). The phenomenologists argue against all three paradigms believing that mental retardation is “real” only if the individual defines his/her experiences within the boundaries of the label of mental retardation. Within the positivist model, identity development is a result of deficits in “normal development” (Schurr et al., 1970) In this paradigm as with the concept of disability, identity as a concept is treated as a fixed state, holding constant across domains (Waterman, 1999). There is fierce criticism of this model and its tenet that disability is seen as an individual biological deficit rather than a social construct. The assumptions in this model leave no opportunity for those who are researched to have a voice that is considered authoritative. Those researched are viewed as the *other*. Table 2.1 found at this end of this chapter provides a summary of the conceptualization of identity and disability by paradigms.

Overview of Relevant Theoretical Literature on Identity and Intellectual Disability

Table 2.2, provided at the end of this chapter, offers additional detail of the major theorists and their assumptions regarding intellectual disability as it relates to the identity making process.

Social Interactionism

The foundation for the majority of theoretical work in the conceptualization of disability and identity making originates in the social interactionism paradigm. In this framework, Edgerton's (1967) work, *The Cloak of Competence: Stigma in the Lives of the Mentally Retarded* stands out as an exemplar. In his ethnographic research with adults who were "mildly mentally retarded" (sic) and leaving institutions, he theorized that individual's primary motivation was to pass as "normal" and to deny one's institutional experiences. The experience of institutionalization socialized these individuals for incompetence in community life. Upon leaving the institution, persons donned the "cloak of competence" in an effort to pass. Typically this effort led to feelings of stigmatization, depression and poor self-esteem. This theoretical work developed from the empirical research of the UCLA Sociobehavioral Group, one of the research groups of the UCLA Mental Retardation Research Center, which will be discussed in a later section.

The UCLA Sociobehavioral group's research marks one of the earliest ethnographic efforts in the use of life histories rather than clinical observations with a sample of persons with intellectual disabilities. Edgerton (1986) cites the lack of research about the effects of the process of labeling. "It is the sub-culture within which persons are socialized that determines their competence, not the event of labeling. This is, of course, perfectly consistent with "'labeling' or 'societal reaction theory'" (p. 124).

Goffman's stigma/labeling theory. Equally compelling and complementary to Edgerton's work is Erving Goffman's (1963) social stigma theory. Society stigmatizes or devalues those who are different as defined by those in power to define (e.g. medical professionals and educational systems). Those who are in a devalued position are in constant internal struggle to not accept this label. The wide range of Goffman's social stigma falls out of the scope of this literature review, which instead concentrates on work related to disability and specifically intellectual disability.

Criticism of Edgerton's, et. al work in stigma research. As with most groundbreaking work, the ideas and research of Edgerton and his UCLA colleagues have endured much criticism. Bogdan (1982) criticizes the work for not questioning the basic assumption of mental retardation, stating that Edgerton merely redefines it as incompetent. Similar to Bogdan's criticism, Finlay et

al. (2003) states that persons in the renamed incompetent category continue to carry a deficit label and are measured against “normality” that is, the dominant group perception. Others (Finlay et al., 2003; Rapley, 2004; Rapley et al., 1998) take issue that the labeling process is something that is “done to” the person with an intellectual disability, with little agency attributed to the individual. Such critics react to the passivity implied in the social interactionist model or criticize from a structural determinist perspective of a power dichotomy, arguing that the stigma approach does not consider the power differentials present in the naming or stigmatizing process.

Crocker and Quinn (2000) present a more sophisticated model of stigma and its impact on individuals’ views of self.

They argue that a number of social factors and mediating psychological processes are likely to influence the meaning of the stigmatizing experience for the individual. The negative impact of stigma is not merely the result of direct social experience. They point out that the social representations of particular groups can be stigmatized, and that these social representations are often well understood by members of stigmatized groups themselves. The model highlights the contextual and dynamic nature of stigma, and the fact that people may hold a range of beliefs about self in relation to disability and stigma. (Jahoda & Markova, 2004, p. 720)

Structualism/Poststructuralism

Review of the literature in the disability studies’ field yields a preponderance of theoretical discussion in this paradigm. (Chappel, 1996, 2000; Chappell et al., 2001; Davies & Jenkins, 1997; Jenkins, 1996, 1998; Oliver, 1990, 1992, 1996) (See Table 2.2) Several scholars in disability studies working in the field of intellectual disability consider themselves poststructuralists (Barnes, 2003; Baron et al., 1999; Goodley, 1998, 2003; Marks, 2002; Rapley, 2004; Rapley et al., 1998; Riddell et al., 2001).

Disability studies literature, in the structural determinist paradigm, emphasizes a larger societal or cultural perspective in terms of viewing disability and addressing change. Poststructural writers add a contextual layer of locating change strategies within the individual. From this perspective, the individual has multiple identities from which he/she can draw upon depending on the context.

Most often, academicians from the United Kingdom, Australia, and Canada frame their work in the structural determinist paradigm, known as the social model of disability. (Barnes, 2003; Baron et al., 1999; Chappel, 1996; Chappell et al., 2001; Crow, 1996; Goodley, 1984, 1996, 1998, 2000, 2003; Goodley & Moore, 2000; Goodley & Rapley, 2001, 2002; Jenkins, 1996; Marks, 2002; Oliver, 1996; Rapley, 2004; Rapley et al., 1998; Riddell et al., 2001) In this model, social and institutional structures are the key to understanding and change. Identification of oppression and resistance are the essence of change. Learning difficulties or intellectual disabilities is the master category of the identity (Baron et al., 1999; Berni, MacArther, & Gaffney, 2008; Davies & Jenkins, 1997). British writers narrate from a class oppression model, while American writers operate from a minority group model (French & Depoy, 2004; Gill, 1997; Hahn, 1995; Roth, 1983; Zola, 1993).

The conversation on how persons with intellectual disabilities fit into this theoretical perspective is more prevalent in non-U.S. writing. In the U.S., theorists have devoted significant attention to persons with physical disabilities or chronic illnesses rather than to persons with intellectual disabilities. (Charmaz, 1995, 2002; Crow, 1996; Thompson; Titchkosky, 2001)

Poststructuralism, originating from European intellectual discourse (Foucault, 1965), assumes that the human body, disability and identity are products of external forces, i.e. that there is a production of power through the control of knowledge. The poststructuralism thinking of multiple identities presumes an individual agency given the context of place and time. Self-determination is considered the capacity to choose and to have choices determine one's actions (Field & Hoffman, 1997).

According to poststructuralist thinking, the discursive practice of professionals has developed a microsystem of social regulation that exercises normative control over individuals and populations (B. Turner, 2001, p. 253). This control extends into the production of research (Marks, 2002). Such control restricts what questions are asked, how they are asked and how are questions investigated.

Positivism

Theoretical thinkers in the positivist framework approach a question as one that has a definite or "true" answer. The challenge is to assemble and appropriately quantify the correct set of data to analyze. In the field of disability this problem frequently is asked as a series of

quantifiable questions related to factors of levels of self-esteem, resiliency or coping, or satisfaction with life. The idea of stigma and the psychological damage incurred by individuals with intellectual disabilities is one such area of study in this paradigm (Szivos-Bach, 1993; Szivos & Griffiths, 1990).

Phenomenologism

There is minimal theoretical work in this paradigm with individuals with intellectual disabilities, although there is a growing body of work with individuals who are physically disabled. Phenomenology by its epistemological nature reflects on the subjective knowledge of the individual. This lack of theoretical work indicates the invisibility that persons with intellectual disabilities around some of life's most important questions.

Overview of Relevant Empirical Research Literature on Identity and Intellectual Disability

Social Interactionism

As described earlier, the works of Edgerton and the UCLA Sociobehavioral group provide this paradigm's foundation from which the majority of empirical research originates (Angrosino, 1992, 1997; Edgerton, 1967, 1986, 1984; Kennann, 1984; Koegel, 1986; Koegel & Edgerton, 1982; Korbin, 1986; Langness, 1994; Langness & Levine, 1986; McCune, 1973; J. L. Turner, 1980; Whitmore et al., 1986; Zeitlin & Turner, 1984, 1988). In addition to the work of individual researchers, the edited book *Life and Culture: Life Histories of Mildly Mentally Retarded persons in American Society* (Langness & Levine, 1986) and *Working Papers of the Socio-Behavioral Group* (Langness, 1994) provide a rich collection of ethnographic work about the historic deinstitutionalization process which occurred with individuals of intellectual and mental disabilities in the 1960's-1970's. Whitmore et al. (1986) conducted ethnographic observation and recordings on Ted, an individual now living in the community. Whitmore's findings are illustrative of the thinking of the UCLA group,

Ted constructs a social reality of events which to an outsider may seem jumbled, confusing, contradictory and sometime irrelevant. But it is the assemblage of purely qualitative experience from the past and present which portrays Ted as he is, and he continues to live his history from day to day. (p. 188)

Zeitlin and Turner (1984) asked the question to forty-six individuals not living in the community, to what extent does the social stigma of disability affect the individual's self-worth. They interpret their findings through a more positivist lens of psychologically based constructs of denier, avoiders, redefiners and acceptors of stigma, which were developed in earlier research. Likewise in a positivist shift, Angrosino (1997) used a life history approach and participant observations, following twenty adults over a two-year period. Trying to understand the relationship between social coping strategies of deinstitutionalized adults and development of a consistent self-image he assigned individuals to the categories of blame attribution, acceptance, denial, and tactical dependence. Others have also explored the stigma, identity process during periods of transition (Higgins et al., 2002; S. Rubin & Heal, 1996; S. J. Taylor, 2000).

Working in the social interactionism paradigm is not exclusive to the U.S.; British, Canadian and Australian scholars conduct research from this perspective. (Beart, 2005; Beart, Hardy, & Buchan, 2005; Craig et al., 2002; Davies & Jenkins, 1997; Epp, 2003; Finlay & Lyons, 1998; Finlay & Lyons, 2000; Finlay et al., 2003; Jahoda & Markova, 2004; Jahoda et al., 1989; Knox & Hickson, 2001; Rapley et al., 1998; Trent, 1994; Whitney-Thomas & Moloney, 2001) Raymond (2000), from the field of education, studied two persons with intellectual disabilities over a one year period. She explicitly states her conceptual framework as labeling and deviancy. Using a collaborative inquiry approach she discovers "for all of use, our stories were about the construction of identity" (p. 6). She finds the same as Bogdan and Taylor i.e. that disability is a social construct, individuals are stigmatized by the label of mental retardation, that it is a self-fulfilling prophecy and the stigma distances people. She substantiates her hypothesis that individuals who are labeled as disabled are subject to being treated differently and if defined as deviant they will experience devaluation and rejection. From a practice perspective she calls upon the educational system to view mental retardation from a social constructionist framework, allowing for potential change in the meaning and reduction of the stigma of mental retardation.

Whitney-Thomas and Moloney (2001), in their qualitative study of eleven students (five without disabilities and six with disabilities), examined self-definition to understand how students develop a sense of themselves and what are the influential contextual factors. While interested in socially constructed meanings they also explore the cognitive processes of self-determination and contextual, adding a positivist component to their work.

Jahoda et al. (2004; 1989) analyzed interviews of persons with mild intellectual disabilities, in addition to paid institutional staff and mothers. They found that persons with intellectual disabilities manage stigma through social comparisons, either by distancing themselves from other labeled persons or by elevating their status, in effect, destigmatizing themselves or through comparison of those persons with more severe intellectual disabilities. The researchers assign these management strategies as one of agency, requiring an active process and an ability to reconstruct an identity. This ability to internalize other's views about oneself contributes to the development of one's self concept (Jahoda & Markova, 2004).

Epp (2003), mixing multiple paradigms, premised his work on role theory and the status attributes of adulthood and investigated the process of identity and sense of integration into adulthood with attributes related to employment, helping others, and a personal sense of independence. He considers identity as related to the "claiming the status of adulthood" (p. 94). In his exploration of the lives of self-advocates he found three themes embedded in the role of an employed worker, relative independence in one's decision making and life style, freedom of social integration within the community and perceived respect from others. Also, from a mixed paradigmatic framework (social interactionism and poststructuralism), Davies and Jenkins (1997) examined how self-identity is formed in response to social interactions from the perspective of cultural discourse, experience and power. They found that persons with intellectual disabilities live with an incongruence of a categorical identity as someone with a learning disability and their self-identity.

While few young people had incorporated the categorical identity of someone with learning difficulties into their self-identity based on their discursive relationships, virtually all of them had done so with respect to other direct experiential relationships. The nature of this categorical identity was further internalized by the differential power relations in which they were involved. (p. 108)

Davies and Jenkins interpreted the label of disability as a master status, which took precedence over other social identities. The categorical identity of disability had direct implications for power and control. They concluded "(P)eople with learning difficulties carry a label and an associated social identity which is a major determinant of their material prospects and the character of their social relationships" (p. 95). These young adults appeared to

experience significant incongruence between their categorical identity as someone with a learning difficulties and their self-identity (p. 95).

Crocker and others (Crocker & Major, 1989; Crocker & Quinn, 2000), found that studies concerning stigma and self-concept substantiate that people with intellectual disability can maintain positive identities by placing value on nonstigmatizing personal characteristics, such as one sees in Seale's (2001) study. Biklen and Moseley (1993), employing a phenomenological approach to life history and participant observation, "document the pattern of people's lives and reveal how research subjects construct meaning around these patterns" (p. 307). Table 2.3 located at the end of this chapter provides additional review of empirical research.

Structural Determinism

Empirical work in the field of intellectual disability and identity also rest on the theoretical assumptions of structural determinism. Inherent in this paradigm is the belief that one's identity is situated based on structural circumstances, such as history, class, gender, disability, status in relation to a power group, or internal/psychological characteristics or human development.

From a human development or psychological perspective Develieger's and Trach's (1999) presented their ethnographic study of high school students with mild mental retardation using life history interviews with focal persons (teachers, coworkers, family members, friends, participants themselves) to examine the process of psychological mediation. According to Develieger and Trach, this internal process integrates life transitions of a person, in the context of a social network. The mediation process provides the connective mechanism between internal psychological processes and external influences of social networks. In the experiences of individuals with intellectual disabilities this also includes the possible internalization of stigmatization effects. Their practice recommendations suggest using the Individualized Education Plan as an important mechanism for assisting the mediation process of transition from high school to employment. Although written from a structural determinist perspective, Develieger and Trach cited Edgerton's (1967) and Langness et. al. (1986) work as influential.

Cunningham and Glenn (2004) investigated the awareness of difference within a social-cognitive stage framework of seventy-seven young adults with Down Syndrome. Using mixed methods, they conclude that awareness and social categorization are significantly associated with

verbal mental age and closely approximated the typical social-cognitive developmental sequence. They define the sequence as the emergence of self-understanding, self-evaluation, social categorization, and awareness of disability and self-categorization (p. 339). Their findings add support to the developmental sequence model in disability (Hodapp, 1990). Their research reinforces the developmental understanding that once children begin to make social comparison and form social categories (approximately 7-8 years old) they also begin to attach value judgments based on their experience and the attitudes of others, this includes the label of disability.

Olney and Kim (2001), using students with learning disabilities, psychiatric diagnosis and brain trauma, questioned that adjustment is staged process of acceptance of the limitations of the disability. Rather, they hypothesize that it is an adjustment process of attitudes toward disability. Their findings suggest

that the formation of an identity that integrated all aspects of the self appeared to be a very complex process for participants. It involved development of a positive self concept and management of the perceptions of others, as well as understanding at multiple levels, the meanings and implications disability had on one's life... This process is related to how the individual made sense of his/her situation and the meaning they attributed to their disability status. (p. 568)

Chappel, Goodley and Lawthom (2001) applied the social model of disability research to persons with cognitive disabilities (p. 45). Using Goodley's earlier ethnographic study of self-advocacy groups, they initiated "a debate about the development of an inclusive social model of disability" (p. 45). They concluded: "resilience and resistance are recurring themes throughout the life stories of many people with learning difficulties" (p. 48).

Poststructuralism

As discussed earlier, more recent thinking originates in the poststructuralism framework (Baron et al., 1999; Berni et al., 2008; Jones, 1992; Rapley, 2004; Riddell et al., 2001; Seale, 2001). This work typically credits a Foucaultian perspective for understanding the production of self or selves.

Rapley (2004), a frequently referenced scholar in disability studies, used a series of case studies to analyze "the interactional production of incompetence" between the person with the

disability (interviewee) and the “expert” (interviewer). He details the psychological concepts and descriptors of “passing” and “denial of disability” and reframes them in the light of competency of those described as intellectually disabled. This process of reframing is a component of a “discursive psychological approach”, which he describes as the “study of those practices and processes by which we produce our selves, as our ‘selves’” (p.18).

Seale (2001) and Riddel, Baron and Wilson (2001) employed a poststructural lens to investigate the multiple identities and points of intersection for persons with intellectual disabilities. Seale analyzed web pages of adults with Down syndrome; finding that persons with intellectual disabilities manage their identities and vary them according to context, allowing for multiple identities.

From a Marxist influenced post-structuralist framework, Riddel et al. (2001) asked: to what extent are lives of adults with intellectual disabilities shaped by the social structures of gender, race, disability and social class or are identities freely chosen? In their ethnographic study of 30 men and women with Downs Syndrome, they find that while all persons possess multiple identities they are deprived of voluntary construction as a result of the master status of a person with an intellectual disability. They conclude that while gender, class and disability intersect, the advantages of gender and middle class are overridden by the negative category of intellectual disability.

Rubin, Bilken, et al. (2001) in their collaborative narrative research used a post-modern/deconstructionist’s approach to interrogate the multiple identities of her co-researcher. Her co-researcher, considered severely retarded in early life, has autism and a communication disability. The themes of freedom, participation, identity and agency figure significantly in their discussion. They explore the body’s relation to performance and the cultural interpretation of the body as well as the person’s with a disability construction of identity. Table 2.4 provides additional details of empirical research on intellectual disability and identity in the structural determinist and poststructuralist paradigm and is found at the end of this chapter.

Positivism

The positivist paradigm dominated earlier research. For example, Schurr, Joiner and Town (1970) reviewed thirty-two articles involving quantitative research focused on self-concept and mental retardation. In organizing this research they identified three themes, 1) general

studies of persons with mental retardation self-concept, 2) the effects of a special class placement on self-esteem and 3) the relationship between self-concept and school achievement. In the first category, researchers used instruments to measure self-attitude and adjustment and “findings are equivocal and generalizations cannot be made about the ‘mentally retarded’s (sic) self-concept” (p. 40). Likewise, in the second category self-concept instruments were used, comparing “low ability and high ability” students in special education classes. Mixed results regarding level of self-esteem between these groups were found. The last theme used achievement and personality tests. Self-concept was considered an antecedent condition to academic achievement (p. 41). From their review of the research the dominance of positivist hegemony is clear in the 1950’s-1960’s. The authors reflected on the mixed results of this positivist framework and suggested that

greater attention might profitably be given to recording and classifying spontaneous self-referent statements. This might overcome one of the major weaknesses of self-concept scales, that they reflect the thinking and biases of the researcher rather than the natural cognitions and concerns of the subject. (p. 42)

They recommended adding a measure to indicate the value that the person places upon an ideal contrasted with the value placed upon his perceived present state. This recommendation fits with the present conceptualization of quality of life.

Endemic to the positivist paradigm is the assumption of one essential identity. Research which investigates self-esteem and stigma oftentimes assumes this essential identity. Gibbons’ study provides empirical research with persons with intellectual disabilities that they did not have lower self-esteem than the general public, despite the stigma of the label of mental retardation (Gibbons, 1985b; Szivos-Bach, 1993; Szivos & Griffiths, 1990).

Additional conceptual work in this paradigm includes Frison, Wallender and Browne’s (1998) quantitative study of 147 African American adolescents investigating the resiliency factors for African American adolescents who have an intellectual disability. Using multiple ethnic identity and risk factor measures they conclude that positive ethnic identity is a possible mechanism for fostering positive outcomes for teens with intellectual disabilities. A significant bias of the study is the assumption that a positive ethnic identity is possible, however, it is not a possibility to have a positive disability identity. Table 2.5 located at the end of this chapter

summarizes significant work in the positivist paradigm regarding identity and intellectual disability.

Phenomenology

Work in this paradigm is grounded with the basic assumption that each one's experience is personal to himself or herself. Knox, Mok, & Parmeter (2000) exemplify use of this paradigm, citing their aims of research as "understanding disability as a personal experience" (p. 59). Using a grounded theory approach and employing a collaborative or emancipatory research method, they interviewed six persons with intellectual disabilities, "through a process of the development of a shared meaning system" (p. 55). Use of the approach provides "an avenue whereby the informants' voice could be heard and valued. In effect, it legitimated both their credibility and the authenticity of their perspective" (p. 58).

Knox and Hickson (2001) examine the meaning of close friendships and identity. While not explicit in their theoretical framework, their works sit in both the social interactionist and phenomenological paradigms. Employing a grounded theory approach to allow for the emergence of issues, this qualitative study focuses on four people with intellectual disabilities and their views of close friendships. "Therefore, a primary concern of research on friendship must be to gain an understanding of friendship from the individual's perspective, i.e. from her or his own frame of reference" (p. 277). Using unstructured interviews they gained "access to each person's interpretations of their own close friendship realities." (p. 286).

Using a single case approach O'Bryne (2001) explored the formation of identity and the experiences of marginalization of a young woman with mild intellectual disabilities. O'Bryne proposed that people with mild intellectual disabilities are vulnerable to social disabilities, both from the effects of discrimination and from the effects of the impairment. She pointed out that those individuals with mild deficits are a distinct subgroup of those with cognitive deficits and are inadequately identified and studied and face serious social breakdown without preventive and supportive measures. The challenge for those with mild intellectual disabilities is manifestation of emotional-social deficits; which O'Bryne considered preventable, manageable or capable of remediation.

She traveled on this hermeneutical journey with the aim to listen to the voices that emerge from the conversation between researcher and subject, asking the question *what does it mean to be human in a particular way?* Her findings reinforce the conceptual thinking that the self emerges as a result of the matrices of both the social and biologic worlds. Referring to the dialogical self, she posits that the self does not incorporate the world, but rather emerges from it. At the end of this chapter Table 2.6 provides additional details regarding empirical research in the phenomenological paradigm.

Summary

This extended discussion on theoretical and empirical work addresses the research need to understand the identity making process of individuals with intellectual disabilities in the context human development. Past and current research explores factors, including, to what capacity a person internalizes disdain/stigma, the relevance of friendship networks on identity making, ethnic identity compared to disability identity, incompetence and identity, the yearning for social recognition, unmet sexual needs, institutional vs. community perceptions of identity and social comparisons between siblings. Much of the research focuses on the “impact” or incorporation of disability on self-definition of persons with intellectual disability. The identity making process is predominantly framed from either the social interactionist perspective of the interactive process of social or contextual factors on one’s sense of self or from a structural determinist perspective of external power sources influencing the identity of persons in oppressed or minority group. The postmodern approach seeks to expand this view and considers multiple identities that each person may possess dependent on the situation. In Rummens framework, discussed in Chapter 1, the literature focuses on the processes of identity construction or identity negotiation with emphasis on a social identity.

While scholars view persons with intellectual disabilities through a singular lens of disability, my research examines the problem does disability even fit in one’s self-definition, or is that “essentialized” characteristic transposed onto the ‘studied’?

Historical Perspective of Provision of Service

Theoretical and empirical research is, in part, understood in the context of history. That is the cultural permutations of mental retardation frame service provision in this field. From a social constructionist perspective, mental retardation is a cultural construction

whose changing meaning is shaped both by individuals who initiate and administer policies, programs and practices and by the social text to which these individuals are responding. Construction (is) sometimes made in the name of science, in the name of care and in the name of social control (Trent, 1994, p. 2).

A post-modern brief historical overview, covering the 19th and 20th century, yields an understanding that mental retardation was first defined as a medical problem requiring medical intervention and then as a social problem requiring social provision. Currently it is produced as a social oppression (Oliver, 1992). Succinctly, science, values/moral and power/control have all shaped the evolution of service delivery (Trent, 1994). One can analyze the history of service delivery by understanding the gazes of those in control of mental retardation; the gaze of pity, fear, knowing, and controlling. (Trent, 1994)

A review of historical work (Braddock & Parish, 2001; Foucault, 1965; Morris, 1969; Parmenter, 2001; Scheerenberger, 1983; Trent, 1994; Weiner, 1993; Wolfensberger, 1969) identifies common cultural and historical markers in defining and providing care and services for persons with intellectual deficits. Society produces the social reality called disability and defines it as the “other”. From the social interactionist perspective, the concept of stigma becomes key to historical understanding. According to Goffman (1963), stigma is any mental attribute that so devalues an actor’s social identity as to disqualify him/her from full social acceptance. Social symbols and language become reinforcers of the stigma, such as the power of naming, eg. disabled, in-valid and dis-eased. This naming serves to create “other”. Disability has been defined as what it is not normal, or the other. The definition of disability and consequently those with disabilities comes from what they are not, that is, how they are not what the majority culture deems of value, i.e. beauty, productivity, mobility and/or articulation. Deviance is not a property inherent in certain forms of behavior, but its place in our worldview is created by those who have the power of naming (Parmenter, 2001).

One can trace services to persons with disabilities through the origin and nature of institutional models designed for addressing the needs of persons with disabilities as well as for societal needs to control this population (Braddock & Parish, 2001; Parmenter, 2001; Trent, 1994; Wolfensberger, 1969). For much of U.S. social history, thinking about and treatment of

those with intellectual disabilities fell into the category of deviant population in general. Society responded in similar ways and held similar expectations for all deviant populations.

An explanation of the U.S. care for the “deviant” population can be understood through prevailing cultural/societal assumptions, religious beliefs and economical/political climate. Early in U.S. history (1700’s) there was a collective pool of misfits or deviants (Braddock & Parish, 2001; Fishley, 1992; Trent, 1994; Wolfensberger, 1969). This pool, included “lunatics” consisting of persons with disabilities (physical, cognitive and mental), witches, criminals, beggars and drunks. Such persons were either “warned out of town” or sent to Houses of Corrections, as protection for decent citizens. “Humanness” equated with Truth, Beauty and Goodness. Those that did not fit this Puritan standard were considered less than human, evil and in need of control. Disability was a result of God’s divine displeasure and such individuals did not have the potential to change to “good” (Braddock & Parish, 2001, p. 25). The House of Corrections, while providing protection from the “other”, was located in the city center and while undesirable, was considered part of the living social world. In 1752, the first general hospital was established in America, with care of persons with mental illness as the primary motive for its creation. Hospitals for the insane, included those with mental deficiencies, and treatment consisted of “assault on the body and the senses” (Braddock & Parish, 2001, p. 26-27).

Another containment or residential option in this early period, included the process of “bidding off.” Until the 1820’s the “defects” were sold or bid off to citizens for the lowest amount, with the government paying private citizens for their care, in essence providing a government funded source of private labor (Braddock & Parish, 2001, p. 27).

Of local interest, Kentucky, in 1793, established a pension system for families too poor to care for their members with mental illness or intellectual disability. This pension existed until 1928. Kentucky was “(o)ne of the first American states to establish provisions for people with intellectual disability and mental illness” (Braddock & Parish, 2001, p. 27).

The hegemony of the 1800’s was one of fear of the other and attaching personal blame. Persons were considered violators of natural law and degenerates. This degenerate pool was large, consisting of persons with mental retardation, mental illness, alcoholics, physical impairments, sex offences, impoverished and immigrants or “foreign stock” (Wolfensberger, 1969, p. 1). The idea of a collective pool of degenerates was reified through the 1920’s when the U.S. Public

Health Services combined criminals, defectives and delinquents for reporting purposes (Wolfensberger, 1969).

In the 1800's, the changing view that disability indicated a personal or family failing came into favor, signaling the idea that one could change. The educational model gained legitimacy resulting in the building of segregated residential schools as the place to educate the 'idiot'. The work of Jean Itard in France with Victor, the wild boy of Avignon, highlighted the hegemonic belief of nurture over nature and the value of education as a "cure" (Braddock & Parish, 2001). Education efforts carried a heavy moral thrust aimed at returning the individual to the community. Complementing this rehabilitative thrust was the belief in medical cures for persons with intellectual disabilities and mental illness. During this period the body became medicalized, witnessed by the accelerated development of mental hospitals or asylums with physicians as superintendents. Persons were considered curable and brief period of optimism ensued related to the curability and rehabilitation efforts taking place in institutions (Braddock & Parish, 2001; Rapley, 2004; Wolfensberger, 1969).

In the later 19th century, after decades of little success in "fixing" the social problem, persons began to be pitied for their idiocy or lunacy (Trent, 1994; Wolfensberger, 1969). Those who were "unfixable" were considered in need of an isolated protective and permanent environment. The comparatively optimistic developmental attitudes of the preceding years deteriorated into pity and charity. The idea of the eternal child or special angel began to take hold in some professional circles and rather than efforts to educate attention turned to taking care of such persons. "Institutions have changed their character, largely to furnish a permanent residence with congenial surroundings for these unfortunates" (Wilmarth, 1902, p. 157, as cited in Wolfensberger, 1969, paragraph 195). Wolfensberger (1969) notes that during this time the benevolent shelter model bore the "seeds of three dangerous trends, 1) isolation, 2) enlargement (of institutions) and 3) economization" (paragraph 197).

In practice, the benevolent shelters were by most accounts, large, crowded, filthy and dangerous institutions, as personal patient/inmate accounts attest. Persons were chained without clothing or heat and physically abused (Braddock & Parish, 2001).

In the late nineteenth century, the U.S. faced major economic hardship as a result of the Civil War. Economic conditions including extensive unemployment brought resultant public

disfavor for those with disabilities who threatened to take the jobs of returning soldiers and other “normals”. The value of education and returning to society declined rapidly (Braddock & Parish, 2001; Trent, 1994). Additionally, those individuals with mild mental disabilities who remained in the institutions provided ready unpaid labor.

By 1900, 11,000 persons labeled as defective lived in custodial institutions, situated in remote farming areas (Fernald, 1917, as cited in Braddock & Parish, 2001, p. 37). These institutions were self-sustaining communities, with residents providing much of the labor. Segregation, resulting in the hiding of “other”, was firmly entrenched in America’s psyche, policies and economics.

Wolfensberger (1969) identified four factors in the early 1900’s that changed the professional and popular perceptions of the ‘feeble minded’. 1) The use of mental tests to scientifically label mental defectiveness. 2) The use of intensive family case histories to legitimate familial or inheritable ‘idiocy’. 3) The use of “scientific evidence” from community surveys, substantiating the negative community impact (crime, immorality) of allowing persons with “mental defects” in the community. 4) Establishing the threat of pervasive and increasing mental defectiveness, through the use of intellectual testing (paragraph 224). Between 1880 and 1925, fear and intolerance of this population rang similar to the virulent anti-immigration fears. Persons of difference were considered a dangerous menace and in need of strict control. “Feeble-mindedness produces more pauperism, degeneracy and crime than any one force... Its cost is beyond our comprehension” (Butler, 1907, p. 10 as cited in Wolfensberger, 1969, p. 21, paragraph 223). Eugenics played a large role in deciding laws, policies, and programs toward this population. Women with intellectual disabilities, in particular, were viewed as dangerous predators.

Girls of the classes described must be cared for by the state... There is no class of persons in our whole population, who, unit for unit, are so dangerous or so expensive to the state. This excepts no class, not even the violently insane. They are much more dangerous and expensive than the ordinary insane or the ordinary feeble-minded or the ordinary male criminal (Bullard, 1910, p. 14-15, cited in Wolfensberger, 1969, p. 21, paragraph 225).

The hegemony changed from persons with disabilities as eternal children, to that of a dangerous burden. Responding to this perceived danger, institutions grew rapidly during this time. In 1904, there were 17.5 persons per 100,000 in institutions and in 1910 22.5 persons per 100,000 (Davis, 1959 as cited in Wolfensberger, 1969, p. 32, paragraph 300). During this era, key scientific discoveries included Binet's standardized intelligence test and Mendel's ideas of inheritance. With "scientific" proof, immigrants and poor citizens were classified as mentally deficient or retardates. Physicians refused to treat infants deemed deficient, allowing them to die. Residents of institutions were routinely sterilized. Again the growth of institutions exploded, in 1923 there were 22.5 persons per 100,000 in institutions (Wolfensberger, 1969, p. 32 paragraph 300). Homes for the feeble minded, asylums, poor farms and almshouses all warehoused persons with intellectual disabilities along other "degenerates or misfortunates" (Braddock & Parish, 2001; Trent, 1994).

Following this wave of hysteria and resultant punitive measures, leaders in the mental hygiene movement began to question the scientific evidence of the dangers of persons with disabilities, including intellectual and mental disabilities. Public opinion criticized sterilization and segregation as failed policies (Wolfensberger, 1969). By 1927, the census of state institutions specifically for persons with intellectual disabilities reached 55, 466 persons (Lakin, 1979, as cited in Braddock & Parish, 2001, p. 41). Between the years 1949 and 1973, institutions routinely performed medical experiments such as lacing food with radioactive elements and exposing persons to hepatitis B (Moreno, 1999 as cited in Braddock & Parish, 2001). In the field of mental illness reforms emphasized the disease model of disability, resulting in the 1930's with experimentation with medical procedures, such as psychosurgeries and electric shock. Persons with intellectual disabilities oftentimes were placed in insane asylums, with the U.S. Bureau of Census in 1940, estimating 29,000 with intellectual disabilities residing in such places (Braddock & Parish, 2001, p. 41).

Concurrently, with the growth of institutions, The 1930 White House Conference on Child Health and Protection recommended a new approach that advocated that persons with intellectual disabilities be identified, supervised and controlled by registration to live in the community. Identification would sort out those who would benefit from community training and those needing segregate facilities (Wolfensberger, 1969, p. 34, paragraph 317). However,

institutions were still considered a humane and cheap way to “combat a social menace” (Wolfensberger, 1969, p. 35, paragraph 319).

Similar to post-Civil War economic conditions, the Great Depression halted any movement toward community reintegration. In fact, the poverty experienced by families of children with disabilities, forced many to institutionalize these children in increasing numbers (Braddock & Parish, 2001; Trent, 1994). In 1935, government intervention in the form of Title X of the Social Security Act, brought specific relief to blind persons (as a result of veteran lobbying efforts). Title V of the same act, authorizing the Crippled Children’s Services, did not consider “children with incurable blindness, deafness or mental defect ...and those requiring permanent custodial care” as within the scope of the act (Social Security Board, 1946, p. 1 as cited in Braddock & Parish, 2001, p. 42) .

During the mid-twentieth century, personal accounts and government investigations raised the public awareness of the abusive conditions in institutions. In the 1940’s, institutions were declared as practicing euthanasia through neglect (Trent, 1994). Community integration movements with governmental backing in mental health, such as the 1946 National Mental Health Act, began taking shape (Braddock & Parish, 2001; Trent, 1994).

By mid-century the state of services presented as primarily a large, rural institutional model of service delivery. The medical profession, with the auxiliary social work profession, encouraged families to place their children in large facilities for the sake of the child as well as for the sake of the family. Parents were urged to leave the child’s care, often for the rest of the individual’s life, in the hands of government and private institutions and to move on with their “normal life”. Farther away from normal life the better it was for the “retardate” and society. Services took on an extremely paternal role often times spearheaded by the family physician. By 1956, 66.1 persons per 100,000 lived in institutions, in 1966 it was 98.7 (Wolfensberger, 1969, p. 32, paragraph 300).

The medical model, rapidly growing in dominance, reached its zenith during this time. As Rapley (2004) suggests, the physician replaced the priest, in his power to control and to name. According to Wolfensberger (2008), prior to the 1950’s, the research in mental retardation focused on describing mental retardation in psychometric terms. From the early 1950’s to mid to late 1980’s, the research and subsequent practice operated from the positivist’s theoretical

background of operant conditioning and behavior modification. Much of this research took place in the actual institutions and later in community based schools and group homes.

In the 1950's, the field of mental retardation saw biomedical breakthroughs centering on the etiology and treatment of mental retardation, notably the treatment of hydrocephaly and the invention of the Halter valve, the early assessment and treatment of PKU, and developments about inherited metabolic disorders and chromosomal disorders.

In synchronization with the positivistic psychological theories and the scientific breakthroughs, the profession and society viewed the person with mental retardation as an object, either a behaviorally dysfunctional object or a collection of maladaptive enzymes or chromosomes. Concurrently, scientific interest in mental retardation faded and moved toward mental health. (Wolfensberger, 1969)

Despite the growing societal unrest in the U.S. and prosperity of the 1950's and 1960's, persons in institutions essentially remained as invisible and/or an 'other', with few to none human rights. It was parents of children (young and adult) who began initial organizing efforts for more humane and educational opportunities for such individuals (Braddock & Parish, 2001). Later, media exposes, such as Geraldo Rivera's 1972 investigation of New York's Willowbrook institution, and the photo essay *Christmas in Purgatory* (Blatt & Kaplan, 1974) raised the consciousness of many public officials and citizens.

The medical model, which gained prominence in the mid-twentieth century, now shares center stage with a model that recognizes the influence or contributions of environmental and social interactional factors. In a 2009 WHO publication addressing medical professionals, the medical model still looms large in the disability services, at the same time paying homage to the rights model of choice and self-determination.

Disability is multifactorial and complex. Interventions to alleviate the disadvantages experienced by people with disabilities need to be appropriate. Responses depend on the disability and on individual choice, and range from medical care through rehabilitation, support services, and psychological interventions, to barrier removal at home, work, school, and in wider society. Because disability arises from the interaction between the person with a health condition and the complete physical, human-built, attitudinal, and

social environment, society's responses to disability must take into consideration all aspects of the experience. (Officer & Groce, 2009, p. 1796)

Since the 1980's a biosocial model of understanding intellectual disabilities predicated much of the research, financing and policy development related to disabilities. This most current era in disability history will be discussed at length in later sections. Officer and Gross (2009) continue to describe disability as an essentialist health condition, but one in which treatment (intervention) depends on the social environment. However, within the quote the authors contradict the essentialist view of a condition to that of disability as an experience. While this frames the concept of disability toward a more social interactional position, the individual with the disability remains defined by his/her disability, whether a condition or experience.

Normalization and Social Valorization

The Normalization Principle figures heavily in the development of the current practice which emphasizes empowerment, inclusion and person centeredness. To briefly place this principle in a historical context, Bank-Mikkelsen, Head of Danish Mental Retardation Services espoused this principle in the 1950's and first proclaimed the concept of normalization as "letting the mentally retarded obtain an existence as close to normal as possible" (Wolfensberger, 1980a, p. 7). Denmark institutionalized this principle into law, with Sweden following in the late 1960's, Nirje, the Swedish Executive Director of the Association for Retarded Children, is credited with coining the term normalization principle (Wolfensberger, 1980, p.7). Nirje defined the normalization principle as "sharing a normal rhythm of the day" with others. as that of others.. (Nirje, 1994, pp. 32-33) This sharing of community customs which includes those of school, home, and work should be available to all, including those with disabilities.

A companion principle to normalization, social valorization rests on the assumption that social roles reflect the behaviors and values that are widely understood, recognized and institutionalized within society. These social roles characterize a particular position within a social system. Historically the social roles proscribed to persons with disabilities have been negative and have assumed little societal value. According to Wolfensberger (2002) social role valorization provides the underlying principle that one may enhance social roles by changing or redirecting behaviors that will raise the social roles of those undervalued.

The social interactionism's essentialism of deviancy replaced the medical essentialism of the 1950's. In the U.S. the practice of the principles of normalization and social role valorization fueled the deinstitutionalization and community integration movement of the late 1960's and 1970's.

Wolfensberger, recognized as a key leader in the normalization movement (Parmenter, 2001), encouraged the controllers of service delivery systems to make the person with intellectual disabilities appear more 'normal'. In practice, this mandate became as large as deinstitutionalization to as small as eliminating yellow buses for students in special education. Society and cultural practices were scrutinized as well as the individuals with disabilities. The "solution" for persons to become full citizens was reduced to "fitting in" to the cultural norms of their community (Parmenter, 2001). This focus on individual adaptation revealed itself in the plethora of social skills curricula for persons with intellectual disabilities from the 1960's through the late 1990's. In practice, alongside this new thinking, the behavioral methods of operant conditioning continued.

Table 2.7 found at the end of this chapter summarizes the historical eras of intellectual disabilities.

Conceptual Framework

The remainder of Chapter 2 presents the conceptual framework for this dissertation, with a focus on understanding the applicable key concepts of McAdams' theory of identity making, and its application to identity making of persons with mild intellectual disabilities, a brief overview of relevant identity literature, including presentation of an alternate framework for understanding the development of identity; and Rummens' model for the process of personal identity development.

McAdams' Theory of Identity Making

This section outlines McAdams' theory of identity making; placing it within the larger picture of social psychology or new trait psychology. McAdams' work in life narrative theory provides the overarching theoretical grounding for this research. Equally compelling are McAdams' identity concepts of redemption contamination, agency, communion, generativity and stagnation in the identity making process.

McAdams and Pals principles of personality theories. In a 2006 provocative article McAdams and Pals argued for understanding personality within the context of five principles. Taken as a whole the five overarching principles provide an organizing tool for understanding species-typical characteristics of human nature, individual difference in common characteristics and the unique patterning of the individual life. (p. 204) McAdams and Pals (2006) place the process of identity making primarily within Principle Three of their heuristic framework of personality theories.

The broadest sweep of human nature is found in *Principle One: Evolution and Human Nature*. McAdams and Pals state that most theories at this level are untestable. At principle one, “personality theorists look to environment and evolutionary adaptedness (EEA) to formulate ideas about basic human design” (p. 206). Basic human design or human social life includes the key dimensions of social acceptance and status.

Principle Two: The Dispositional Signature, includes those traits that “may be seen as the most common kinds of states that a person experiences across situations and over time” (Fleeson, 2001 as quoted in McAdams & Pals, 2006, p. 207). These traits provide a recognizable signature that a person tends to express in a range of situations (though not in all) and over a relatively long period of time” (McAdams & Pals, 2006, p. 207). McAdams (1995) referred to the theories in Principle Two as those of the “psychology of the stranger”. A significant amount of empirical research regarding personality traits fits in Principle Two. Within this principle are the longitudinal studies showing the stability of personality characteristics over time.

Principle Three: Characteristic Adaptations include “the more particularized features of psychological individuality contextualized in time, situations, and social roles” (McAdams & Pals, 2006, p. 208). These adaptations are the variations of individual lives. They include motives, goals, plans, strivings, strategies, values, virtues, schemas, self-images, mental representations of significant others, developmental tasks, and many other aspects of human individuality that speak to motivational, social-cognitive, and developmental concerns. (p. 208)

These characteristics are “more amenable to environmental and cultural influences than are traits... and are more implicated in situationally anchored personality processes and everyday personality dynamics than are traits” (p. 208).

Especially relevant to this dissertation is the distinction that Principle Three is the *doing* side of personality. Theories emphasizing motivation, social learning, coping mechanisms and developmental challenges fit in Principal Three. Citing Cantor (1990), McAdams and Pals distinguish this principle as “most directly implicated in the dynamics of goal-directed, cognitively mediated, role-anchored, and/or developmentally informed everyday behavior” (p. 208). This level addresses choice making and participation. Research conducted within this level has implications for direct practice. Principle Three incorporates the developmental motivations and behaviors of generativity, agency and communion.

Principle Four: Life Narratives and the Challenge of Modern Identity addresses the human individuality found in one’s life narrative. This level is personal meaning making at its core. Not only is it meaning making at the moment, but it incorporates how one keeps the narrative alive and growing. “...it incorporates the reconstructed past and the imagined future into a more or less coherent whole in order to provide the person’s life with some degree of unity, purpose, and meaning” (Habermas & Bluck, 2000; McAdams, 1985; Singer, 2004as quoted in McAdams and Pals, 2006, pp.210-211). Personal agency assumes primary importance at this level.

Principle Five: The Differential Role of Culture at this level, McAdams’ and Pals’ concepts and distinctions tend to blend, providing less clarity between principal four and five. As the authors state,

By their very definition, characteristic adaptations are situated in particular social, cultural and developmental contexts. Goals and interests reflect personal investments in activities, programs, and life trajectories that society makes available for the individual. (p. 211)

And again, “(L)ife stores are the center of culture (Rosenwald & Ochberg, 1992 as quoted in McAdams & Pals, 2006, p.211). McAdams’ recent work, (2006b) *The Redemptive Self*, centers on the cultural impact on the life narrative, in particular the redemptive narrative.

Indeed, a person’s life story may say much about the culture wherein the person lives as it does about the person who lives it and tells it. Life stories draw on the stories that people learn as active participants in culture- stories about childhood, adolescence,

adulthood, and aging. Stories capture and elaborate metaphors and images that are especially resonant in a given culture. (McAdams & Pals, 2006, p. 211).

McAdams summarizes that,

the five fundamental principles suggest a broad outline of what scientists, practitioners, and other informed scholars should be thinking about when they seek to make psychological sense of the individual human life... Taken together, the five big principles assert that dispositional traits articulate broad variations in human functioning, that are recognizable, in part, for their evolutionary significance but that more contextually nuanced and psychologically constructed features of personality move well beyond broad traits in speaking directly to how human beings respond to situated social tasks and make meaning out of their life in culture. (p.205)

Figure 2.1 located at the end of this chapter provides illustration of the Five Principles used in making psychological sense of the individual life.

Application to Identity Making of Persons with Mild Intellectual Disabilities

Specifically, Principles Three (Characteristic Adaptations) and Four (Life Narratives and the Challenge of Modern Identity) provide the conceptual framework for this dissertation. Principle Three addresses the analytical constructs of agency, communion, and generativity and recognizes the active part that one has in identity making. McAdams and Pals (2006) place the process of identity making primarily within Principle Three of their heuristic framework of personality theories. The identity of a person with intellectual disabilities is certainly contextualized to her place in time, situations and social roles. Nijre's (1994) and Wolfensberger's (2000) works on devalued social roles for a person with disabilities directly addresses Principal Three. How one adapts is the variation of individual lives found in Principle Three.

Principle Four, understanding the life story, using McAdams' identity framework, sheds light on the pattern of adaptation for individuals who are culturally in a devalued role but who may be moving into a more valued role, through the person centered planning process. Taken together, Principles Three and Four, include the exercising of personal agency, such as, more control and increased decision-making, which is underpinned by the motivational, social-cognitive and developmental process inherent in Principle Three. Exploring the identity of

individuals with intellectual disabilities through their life story allows the discovery of patterns of motives, goals, plans, schemas, and self-images within a human development context. Increased self-advocacy and the person centered planning process situate these personality processes in a moment in time. The process recognizes the uniqueness and complexity of the individual's narrative, the inherent capability of personal agency (choice, control of one's destiny, decision-making) and the importance of communion (inclusion) in its value of citizenship.

The person-centered process itself is a narrative tool for individuals to tell their story, including their remembered past, perceived present and anticipated future. The interactional process with one's circle of support allows one to make desired changes in one's present life and to plan for the anticipated future. The normative principles of self-determination, autonomy and independence, love and acceptance, community status and continuous growth are recognized as basic human needs and capabilities. (Brost & Johnson, 1982; C. O'Brien & O'Brien, 2000, p. 16). The condition of disability is relevant only to the extent that the disabling condition complicates the fulfillment of these needs for power and love. In McAdams and Pals' framework these themes of power and love are defining characteristics of the processes of Principle Three. My research addresses the extent to which disability influences the themes of power and love in one's life story narrative. If there is an influence impact, what is this influence? Figure 2.2 at the end of this chapter illustrates the application of McAdams' identity making process to persons with intellectual disabilities.

Review of application of McAdams' Theory within the Disability Field

McAdams' conceptual framework is underused in the field of disability research, yielding two dissertations, (Marshall, 2007; Rayburn, 2003). Rayburn's research focused on families' understanding of themselves using the concept of stigmatization to explore the relationships between family members and human development. Marshall's poststructuralist work explored the identity formation of women who have been diagnosed with the genetic condition of Turner Syndrome. She used semi-structured interviews with twelve women, ages 18-27 years; investigating identity formation employing three models, 1) grounded theory, 2) analysis of performance, and 3) discrete life story content analysis. McAdams' themes of agency and

communion and sequences of redemption and contamination were employed for the life story content analysis.

Identity Status Literature by Paradigm

Structural Determinism

Returning to the earlier paradigmatic discussion in Chapter 2, the structural determinist literature *figures* heavily in the identity status literature (Bosma, Graafsma, Grotevant, & de Levita, 1994; Cote & Levine, 2002; Erikson, 1963; Kroger, 1986, 1989, 1993, 2000; Marcia, 1993; van Hoof & Raaijmakers, 2003; Waterman, 1999). In this paradigm one has a consistent identity across domains. Van Hoof and Raaijmakers (2003) provided an excellent overview of the debate on the structure of identity formation, paying particular critical attention to Marcia's and Kroger's theories of status model for identity formation. Van Hoof and Raaijmakers called for a search for the structure of identity formation in order to understand identity, identity changes and identity development (p. 271). They called for a movement away from the structure of identity formation toward the concept of structural integration.

For purposes of this identity literature review the conceptual thinking in the area of structural identity formation will be briefly summarized. While this research proposal does not employ this particular conceptual framework it is discussed only to present an alternate conceptual model.

Similar to the narrative identity approach, Erikson's (1968, 1980) theory on identity formation is cited as a key text in this structural identity field. Narrative and structural identity theorist agree that adolescence and adulthood constitute the developmental stage for identity development. For Erikson, the end of adolescence signals an identity crisis whereas identity formation is a lifelong development primarily unconscious process (Erikson, 1980, p. 122)

Kroger (2003) differentiated between soft and hard structural stages of identity development, claiming her model as "soft structural stage model". Within this soft structural stage model lies the identity status approach, exemplified by Marcia's four status of identity development. Marcia (1966, 1993) developed a four status model which identifies the progressive stages of identity development. These stages include foreclosure and achievement, moratorium and diffusion. Two dimensions, crises and commitment, determine the development of the status. (See Tables 2.8 and 2.9 at the end of this chapter.) Those in the foreclosure status

structure their identity on the basis of identification with significant others. Those in the achievement status structure their identity on the basis of self-chosen values and interests. (Kroger, 2003) On the continuum of developmental hierarchy, foreclosure status is developmentally less advanced than the achievement status.

The conceptualization of identity types -social, personal, collective and ego, discussed previously in Chapter 1 and considered in this chapter, could potentially provide another layer within the status framework. Within the status structure one could place the identity types and describe each type from a status perspective. Marcia and others (Kroger, 1989, 2000; van Hoof & Raaijmakers, 2003; Waterman, 1999) instead proposed the study of the domains or contexts of identity formation, such as work, leisure, religion, and the dimensions of the domains, i.e. friends, gender role, sexual expression. Sophistication of this model accepts that we do not develop all domains equally or at the same time. Kroger (2003) considered this appreciation for the importance of personal significance of specific domains as understanding the demonstration of structured wholeness. Van Hoof and Raaijmakers (2003) concurred that “the personal salience of an identity domain is crucial for determining the structure of identity”(p. 277).

The hard structure model prioritizes the mental operations that control and organize identity formation and development, such as Piaget’s cognitive developmental approach (van Hoof & Raaijmakers, 2003). The soft model approach considers the underlying hypothetical constructs of identity formation, such as Marcia’s status model. Consistent with the assumptions of the structural determinist paradigm, Marcia provides the following definition of identity: “identity is a self-structure- an internal self-constructed, dynamic organization of drives, abilities, beliefs, and individual history (Marcia, 1980, p. 159, as quoted in van Hoof & Raaijmakers,2003, p. 279).

Of interest to this research is Mackey’s (1999) investigation of the possible relationship between McAdams’ narrative conception of identity development and Marcia’s identity status identity development. Reporting on a descriptive study of a sample of one hundred and thirty one high school students, she suggests that

clarity and coherence of narratives were significantly positively related to the development of vocational identity status on the Marcia measure, as predicted, but not to the development of religious identity status... The findings indicated that there was only

a modest overlap between the identity status constructs of Marcia, and the life story narrative construct of McAdams. It appears that these are two reasonably distinct frameworks for studying identity development, at least during this mid-adolescent period. (pp. i-ii)

Social Interactionism

Social constructionism or interactionism also significantly informs the identity literature. Work in this area primarily conceptualizes identity through a deviancy lens. (Becker, 1963; Estroff, 1981; Goffman, 1963; Ogden, 2002; J. S. Strauss, 1994, 2000). Key thinkers in the field of social identity and deviancy include G.H. Mead (1934), Berger and Luckmann (1967) and Blumer (1969). From the social constructionists' lens, identity is seen as fluid across time and space and contextual in nature. Much of the work developed in this paradigm is conceptualized in a larger sociological perspective. Earlier discussion regarding the literature review of theoretical and empirical research in the field of disability addressed the relevant literature.

Poststructuralism

In one sense the poststructuralist perspective offers a compromise to the opposing thinking of the social interactionist and structural determinist paradigms. Poststructuralism opines that while one's identity is bounded by developmental or structural conditions one's place in the larger historical context or circumstances related to various situations and/or opportunities open up the possibility that identity will change over time and that one may have multiple identities at any given time. (Gergen, 2001; Howard, 2000) McAdams' theory of narrative identity and his sense of self as fluid and open to renegotiation due to cumulative historical societal and personal influences offers an intellectual reckoning between social interactionism and fixed structural determinism.

McAdams, Narrative Theory, and Identity

McAdams (2001, 2006b; 2006) joins others in the study and development of narrative theory. (J. M. Adler, 2008; J. M. Adler & McAdams, 2007; J. M. Adler, Wagner, & McAdams, 2007; Bruner, 1986, 1987, 1990; Gergen & Gergen, 1986; Kleinman, 1995; Polkinghorne, 1988; Singer, 2004) For many in this genre, life stories and identity are one and the same (Polkinghorne, 1988). Identity is fluid and is reworked throughout the life course. Identity is the integrating piece for the multiple selves of an individual; it ties roles together. McAdams

considers identity as the one central structure which possesses the plasticity to incorporate multiple roles or characters

if identity takes the form of story, then the different selves in one's life embodied in the multiple roles one assumes in daily life may be seen as potential characters in the story. Among other things, stories are about characters, who act, interact, desire, think and feel. As we move through early and middle adulthood, identity challenges us to construct a personal myth in which a sufficient number of different kinds of characters may emerge, develop and thrive.... [I]t is the story with which the characters are given, form, function and voice. (McAdams, 2001, pp. 117-118)

Adler (2008) highlighted the differences between the scientific or positivist paradigm and the narrative mode in understanding identity. The positivist mode is concerned with logically categorizing the world. The narrative mode, a term used by Bruner (1986), is "concerned with the meaning that is ascribed to experiences through stories" (J. M. Adler, 2008, p. 423). Bruner (1986) explains that these stories are about "human or humanlike intention and action and the vicissitudes and consequences that mark their course" (p. 13 as quoted in J. M. Adler, 2008, p. 423). These stories rely on the individual's perception about his/her life. The positivist paradigm

seeks to explain the underlying relationships between sets of observable variables while thought grounded in the narrative mode seeks to explain the storied meaning people make of these relationships. Each mode of thought has significant strengths. (J. M. Adler, 2008, p. 423)

The field of narrative study of lives developed during the past several decades by a multi-disciplinary group of academics. Those employing this theory agree that an individual's identity is comprised of the stories he or she constructs about his or her life. An overarching premise of this theory is that persons incorporate their reconstructed past, the perceived present and anticipate future in their life story/identity. This sense of cohesion provides a unity and purpose to individuals' lives and stories of themselves. (McAdams, 2001, 2006b). This sense of cohesion offers "a modicum of direction, vitality, and followability" to one's life story in a postmodern world. (McAdams & Bowman, 2001, pp.11-12)

J. Adler (2008), credits McAdams' (his former research advisor) as developing the theory of narrative identity and acknowledges that McAdams and the Foley Center for the Study of Lives lead the social psychology field in current empirical narrative research. As Adler states

It is worth noting that narratives can be studied from within a paradigmatic framework.

Much of McAdams' work, and mine as well, treats individuals' narratives as the raw data for a scientific exploration.(J. M. Adler, 2008, p. 423)

McAdams' recent book, *The Redemptive Self: Stories Americans Live By*, (2006b) details the construction of redemptive stories and the relationship to mental health and quality of life. Chapter 3, Methodology, further details this relationship between narrative theory and positivist methodology.

Agency and Communion

Key to McAdams' narrative theory are the concepts of agency and communion. Identity theorist frequently evoke David Bakan's ideas (1966) on agency and communion. Bakan (1966) stated

I have adopted the terms 'agency and communion' to characterize two fundamental modalities in the existence of living forms, agency for the existence of an organism as an individual, and communion for the participation of the individual in some larger organism of which the individual is a part. Agency manifests itself in self-protection, self-assertion, and self-expansion; communion manifests itself in the sense of being at one with other organisms. Agency manifests itself in the formation of separations, communion in the lack of separations.... One of the fundamental points which I attempt to make is that the very split of agency from communion, which is a separation, arises from the agency feature itself, and that it represses the communion from which it has separated itself.... I conceive of agency and communion at a rather high level of abstraction, as manifested in various ways and in various contexts. (p. 15)

From this opening discussion, one witnesses the psychoanalytical assumptions which frame his argument. Upon reading further, the Judeo-Christian belief of duality, and its implications of evil vs. good; evil considered a result of separation (from God), and agentic behavior. Bakan cited studies from the 1950's to confirm his idea of male-agentic and female-communion, and also considers the differences between male and female sexual functions and

physiology to ground his argument about differences between men and women and agency and communion. He cautioned on the negative effects of unmitigated communion and agency on psychological and physical well-being.

Bakan's ideas on communion and agency provided key conceptual thinking for the still frequently used Bem Sex Role Inventory (Bem, 1974) and Personal Attributes Questionnaire (Helmreich, Spence, & Wilhelm, 1981). These two instruments measure gender role perceptions and masculine and feminine personality characteristics predicated on the constructs of agency and communion. Sex role researchers continue to argue the merits and faults of defining agency and communion using the unidimensional gender categories (Hirokawa & Dohi, 2007; Li, Tseng, Wu, & Chen, 2007). Hirokawa and Dohi (2007) cited previous studies that showed positive agency to be associated with psychological well being. Studies also showed communion "to be related to increased social support which promotes healthy behavior and satisfactory interpersonal relationships" (p.517). Hirokawa and Dohi employed Helgeson's (1994) conceptual model of the relationships of biological sex, agency and communion to psychological and physical well-being. In this model, Helgeson considered self-control, over-involvement with others and social support as mediators between unmitigated agency/communion and psychological well-being or depression. Hirokawa and Dohi applied the Helgeson model to their study of Japanese young adults. In their study both males and females scored higher in communion than agency, underscoring the influence of culture on agency and communion and mental health.

The concept of agency plays significantly in the identity literature (Cote & Levine, 2002; Geertz, 1973; Kleinman, 1995). Cote's and Levine's (2002) *Identity formation, agency, and culture: A social psychological synthesis* presents identity formation as it relates to individual agency and social organization (culture). They employ Erikson's developmental ideas while also incorporating postmodernist and feminist thinking. Kleinman (1995) states that "personal identity emerges in this process of entering into and finding a structured place within the flow of experiences" (p. 124). He writes of one's active search for "being".

McAdams considers agency and communion as the foundational blocks for understanding identity; and predictably that one understands identity by understanding the life

story. At different developmental stages in one's life the driving forces of agency and communion take precedence over the other.

Disability and agency and communion. Jenkins (1996), in his research with persons with intellectual disability and self-identity, referenced the philosopher, Charles Taylor's, ideas about the intersections of citizenship or participation in the world and individual agency. He specifically considered Taylor's (1989) belief that that the act of agency in relation to a collective humanity links together the two primary life concepts - communion and agency. Rubin et al. (2001) focused on the concepts of independence, participation and intellectual competence and their relationship to the concepts of democracy, freedom and identity, from a nonessentialist perspective. The authors presented their postmodern perspective to explore the multiple identities of one individual, Rubin. (Rubin was considered severely mentally retarded in early life. More accurately, she has autism and a communication disability.) The authors cited Maxine's Green's (1988) ideas of freedom and participation when considering the definition of identity. They employed Greene's description of freedom as "the kinds of conditions in which people can be themselves" (Kohli, 1998 as cited in Rubin, 2001, p. 415). According to the authors, Green's concept of agency is the essence of what makes a person free. And "being" free are those processes of acting and choosing and deciding.

The person choosing breaks the chain of causes and effects, of probabilities, in which he normally feels himself entangled. He breaks it in part by asking "Why" by perceiving the habitual itself to be an obstacle to his growing, his pursuit of meaning, his interpreting and naming his world. (S. Rubin et al., 2001, p. 415, quoted from Kohli, 1998, p. 7, citing Greene, 1988)

Taylor's ideas are also evident in Rubin's study, i.e. the authors make the connection that personal freedom or agency is associated with the desire for communion or participation as a citizen in the world.

The previous discussion highlighted two works in the disability field that consider the concepts of agency and identity. However, few writers in the field of intellectual disability (Epp, 2003; Field & Hoffman, 1997; Jenkins, 1998; Riddell et al., 2001; S. Rubin et al., 2001; Watson, 2002) have regarded the idea of agency as crucial to identity making and self-concept for persons with intellectual disabilities. This absence in the disability research of a key concept that

prioritizes an individual's humanity (agency) speaks to the cultural and research assumption that agency is not proscribed to persons with intellectual disabilities.

Casting a wider net in the identity literature. A review of the identity research literature focused on understanding the lives of persons with mental illness presents a richer picture than that found in the intellectual disabilities research. The common denominator of both populations significantly devalued and stigmatized by society, offer an opportunity to consider this area of research. Once again, Charles Taylor's (1989) ideas frame the discussion. Barham and Hayward (1995) employed Taylor's humanity and moral good framework in their work regarding persons with mental illness. Using Taylor's conceptual framework they considered the "options and constraints which different groups of people confront in attempting to satisfy their craving to be 'rightly placed' in relation to the good" (Barham & Hawyard, p. 141).

J. S. Strauss (1994) used a life history/narrative approach to interrogate the process of identity formation for persons with schizophrenia. Opening the net wider regarding devalued persons, Athens (1974, 1992, 1994, 1997) also employed a life history/narrative approach. Both developed typologies/categories to explain the phenomena studied. Analyses from Athens' interviews yields a rich theory on human development, understood through constructed typologies for all persons not only those who become violent perpetrators. His work explores universal processes and the nature of self.

For Strauss the sense of self is the central and mediating factor in the areas of daily functioning. Using a life context approach, Davidson and Strauss (1995) construct categories for understanding the recovery process for a mental illness. Their category of intentionality employs Husserl's phenomenological concept of agency. Use of typologies is not uncommon in the studies of persons with disabilities and identity development and other human processes. (Angrosino, 1997; Olney & Kim, 2001; Zeitlin & Turner, 1988)

Athens' work (1974, 1992, 1994, 1997), with violent criminals and Strauss' work (1994, 2000) with persons with schizophrenia, provide excellent examples of placing devalued groups within a universal developmental process which incorporates the ideas of citizenship and agency. Their work expands our understanding that humans, regardless of their label are more similar than different.

Conceptual Model for the Process of Personal Identity Development

My research argues for the need to include the life stories of persons with intellectual disabilities within the context of a universal development model. This development model includes concepts from McAdams' life story approach as well as Rummens' (2000, 2003b) concepts regarding identity and the identity making process. The following section provides a more detailed explanation of Rummens' approach to the conceptualization of identity, which was briefly discussed in Chapter 1.

Rummens

Rummens (2000, 2003b) employs a multi-dimensional approach in her conceptualization of identity. First, she conceptualizes identity in terms of relational constructs, personal, social, and ego. She then distinguishes between the process of identity making; identity formation, or development; identity construction and identity negotiation. Identity is viewed from both a relational and contextual perspective with the act of identification viewed as inherently process driven. Rummens then overlaps the process and the type of identity with consideration of time and change over time. The idea of identity (What is my identity?) can change with context as well as from the perspective of the parameters of identity formation or type. Identity is not one fixed state.

Rummens considers the inherent processes of identity with each identity type, i.e. social, personal and ego. The process of identity formation, addresses the question *how do I fit in the world and* the process of identity construction addresses the question *what are the major reference groups or individuals that have influenced who I am?* The third process, identity negotiation, more sociological in nature, asks the question *what is the political nature of my personal and social identifications?* (See Table 2.10 at the end of this chapter.) Erikson's (1968) definitions of identity types provides the basis for Rummens' definitions.

Erikson distinguished between several dimensions of identity; ego identity, personal identity, self-identity, social identity... Ego identity is the most fundamental dimension that encompasses the other elements. Ego identity gives structure to all dimensions of personality and integrates them so that there is continuity between past and present (time) and across social roles (space). Self- identity integrates self- and role-images and is part of ego identity. Social identity finally, consists of the identification or solidarity with the

values or ideals of a certain group, or the internalization of elements derived from the groups to which one belongs or with which one identifies. Central to identity is thus the integration of experiences, internalization, ideals, values, and so on. (van Hoof & Raaijmakers, 2003, p. 279)

Research in the disability field centers on 1) the processes of identity construction and identity negotiation and 2) the collective identity examined from both the deviancy model and social model prevalent in British research. Personal identity and identity formation with its significant question *How do I fit in the world?*; is the primary position in this research. The narrative or life story approach used by McAdams' (1996) best addresses the approach needed to interrogate this question. Equally relevant is McAdams' developmental approach, fashioned from Erikson's core ideas of stage development within contextualized factors of time and place. McAdams' life story framework provides an alternate framework to the identity status model, described earlier.

Rummens describes the process of identity formation using constructs of attachment, sense of belonging, and self-competency while McAdams uses the terms communion and agency to describe the constructs involved in the process of identity formation. McAdams' categorization offers a broader conceptualization than Rummens, Rummens'; addressing the concepts of attachment and sense of belonging within the communion concept and self-competency within the agency concept.

Process of Personal Identity Development and the Role of Agency and Communion

One can explore and understand the process and sense of personal identity development through the use of a series of questions, addressing the basic concepts of agency and communion. The overarching question is *How do I fit in the world?*

- Agency: Do I control or how can I control my life and what happens to me?
- Communion: Who (can) (does) love me?
 - Whom can I love or how can I love others?
 - What is my place in the world of others?
 - What do I have to give to others?

Agency

Referencing McAdams' Principle Three, to conceptualize agency one considers internal motives and behaviors. In the research literature the motives associated with agency include autonomy, empowerment, self-esteem, locus of control, need for achievement, mastery and competency. Behaviors associated with agency include choice making, participation, goal setting, goal attainment, and freedom. Measures of these concepts include investigation of participation in social roles, quality of life indicators, personal (self) perception of agentic behaviors, social well-being, and psychological well-being. McAdams' provides a coding system for themes of agency and communion in analyzing the Life Story Interview. (See Chapter 3 and appendices.) McAdams' study of agency considers the presence of four themes, achievement or responsibility, power /impact, self-insight and status/victory.

The exploration of these concepts may occur at any developmental stage. For adults, Erikson's developmental stage of generativity vs. stagnation provides the structural address for the concept of agency. Generativity presupposes an agency; an ability to produce. Inability to do so defines stagnation.

Communion

The internal motives for communion include the concepts of affiliation and nurturance, interpersonal relationships and need for intimacy. Behaviors associated with communion include participation and identification with social networks. The four communion themes explored in McAdams' Life Story Interview are love/friendship, dialogue, caring/help, and unity/togetherness.

In the generativity vs. stagnation stage one assumes a desire or need to be larger than one's self, to contribute to the next generation. The communion concept, like agency is crucial at the generativity stage.

Redemption and Contamination

McAdams frames the individual's life story as either redemptive or contaminated. He cites the theoretical work of Tomkins (1987) Carlson (1988) and Tedeschi and Calhoun(1995) as influential in the understanding of redemption and contamination within the life story.

Tompkins's script theory offers a shift in psychological theory from a psychoanalytic framework to narrative or progressive life story framework. Carlson provided not only empirical studies from this perspective but added to the conceptual development of script theory.

“According to Tomkins, human beings are fundamentally like playwrights who create scripts in which they play the leading roles” (McAdams, 2006b, p. 222). From this perspective one understands the life story in units of scenes, consisting of characters, props, places, and actions. The scenes describe the action and the scripts are “formed as a person constructs idiosyncratic “rules” for interpreting, creating, enhancing or defending against a family of related scenes.... A script tells us “what to do about” any set of scenes” (Carlson, 1988, p. 107). A series of scenes or experiences will establish psychological patterns, which spell out the life story, in terms of the past, present and anticipated future. Carlson defines two ways of constructing links with one scene to another. The analog process involves the cognitive process of generalizing, “this is happening again” and the variant process, identifies the differences in the experiences. (Carlson, 1988, p. 108)

Of relevance to McAdams’ concepts of redemption and contamination are two of Tompkins (1987) script structures, nuclear and commitment.

“Commitment scripts involve the courage and endurance to invest and bind the person to long-term activity and to magnify positive affect by absorbing and neutralizing the various negative costs...”(p.167).

Nuclear scripts arise from the unwillingness to renounce or mourn what has become irresistibly seductive and the inability to recover what has become lost, to purify or integrate what has become intolerably contaminated or conflicted, and to simplify or unify what has become hopelessly turbulent in complexity, ambiguity or rate of change. (p. 197)

McAdams’ Coding Systems for Contamination directly credits Tompkins’ (1987) nuclear script and the idea that “a very good scene turns very bad”. Similarly, McAdams’ conceptualization of redemption stories shares commonalities with the commitment script. Carlson (1988) describes the commitment scripts as based on
1) a fortunate predominance of positive affect... and models who may exemplify commitment to “improving” some less than ideal conditions. 2) Setbacks in the pursuit of goals typically result in deepening rather than abandoning- the original commitment. This capacity for absorbing punishment may be a unitary feature of commitment scripts. (pp. 110-111)

McAdams expands on this and explicates redemption in terms of four themes; redemption imagery, enhanced agency, enhanced communion and ultimate concerns. Figure 2.3, at the end of this chapter, illustrates the linkages between McAdams Life Story concepts.

Research Questions

1. What experiences influence the formation of identity for sampled persons with mild intellectual disabilities?
2. What are the common themes that offer insight into the developmental processes that lead to
 - a. Communion
 - b. Agency
3. Are there similar and different response patterns of communion and agency within the sample?
4. What are the common themes that offer insight into the developmental processes that lead to a
 - c. Redemptive Narrative Story
 - d. Contaminated Narrative Story
5. Are there similar and different response patterns of redemptive and contaminated narrative story within the sample?
6. How do the narrative themes of generativity and stagnation show themselves?
7. Are there similar and different response patterns of the themes of generativity and stagnation within the sample?
8. Are there other contributing factors in the identity making process that are not described by the communion, agency, or generativity?
9. What is the influence, if any, of disability in the experiences of the sampled persons?

Table 2.1 Conceptualization of Identity and Disability by Paradigm

Paradigm	Assumptions of Reality
Structural Determinists	<p>Identity is primarily determined by internal development stages, or external forces such as gender, disability, class, race, sexual orientation</p> <p>Disability is determined by external forces which define ability/disability as it relates to the economic and political needs of the state.</p>
Poststructuralist	<p>Identity is fluid, nonstatic. One has multiple identities depending on context.</p> <p>Disability is a product of discourse, there is an external social production of the human body, which is socially, economically and politically regulated (Turner, 2001; Foucault,1965)</p>
Positivists	<p>Identity is a fixed/essential state.</p> <p>Disability is a result of a deficit in the body whether mental or physical. Both identity and disability can be quantified.</p>
Social Interactionist	<p>Identity is a social construct, determined by historical and contextual factors of time, place, environment, and economics. The individual has an agentic part in the identity making process</p> <p>Disability is a social construct determined by historical and contextual factors of time, place, environment, and economics. The definition of disability changes with changes in the above factors.</p>

Table 2.1 (continued)

Paradigm	Assumptions of Reality
Phenomenologist	<p>Identity is a result of personal exploration</p> <p>Disability is a subjective experience, within the “lived body” or embodiment of the human experience; there is no separation between the body and the mind, and we are grounded in the relationship between embodiment and the world. (Turner, 2001, pp. 253-255).</p>

Table 2.2 Review of Major Theoretical Work in Field of Disabilities

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
Edgerton (UCLA Socio-Behavioral/Mental Retardation Center) 1960'-1980's US	There is a socialization process that occurs with the application of the label mentally retarded -A stigmatized status results in attempts to over-come spoiled identity and to "pass" as normal.	Social Interactionism/ Stigma	Large deinstitutionalized population of persons with i.d. Life histories of persons with i.d.	Goffman, Mead, Blumer	-Early work focuses on stigma making process during deinstitutionalization of large settings for persons with i.d. -Multidisciplinary research center Group did not question the label of mental retardation, i.e. the social production of it, rather the effects of the label.

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
	<p>-Persons with i.d. find the label dis-crediting and avoid or deny label becoming attached to them.</p> <p>-Acceptance achieved primarily through conformity</p>				

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
<ul style="list-style-type: none"> • Langness and Levine 1986 • UCLA group 	<p>-Mild m.r. (sic) is social and cultural phenomenon rather than a medical, genetic, cognitive, or psychological condition.</p> <p>-Traditional success markers or indicators of life stage transitions are unavailable to them.</p>	<p>Social Interactionism/Stigma</p>	<p>As above</p>	<p>Goffman, Edgerton</p>	<p>-Without markers of transitions and success and with marginal status persons with i.d. suffer from serious loss of self-esteem.</p>

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
Angrosino 1992 UCLA group	<p>-Persons with i.d. develop adaptive coping strategies that can be classified by typologies.</p> <p>-There is an association between coping strategies and the development of consistent self-images.</p>	<p>Social Interactionism/Stigma Linguistics</p>	<p>Life histories of persons with i.d.</p>		<p>-Implicit rather than explicit meaning is important to analysis</p> <p>-Life history contributes to the understanding of how “deviants” manipulate symbolic forms in order to adapt and communicate with the mainstream culture.</p>

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
Wolfensberger 1980 US	Deviancy does not come internally from the devalued person but within the imposed social roles, the values and perceiver's interpretation.	Social interactionism/Stigma	Clinical work with individuals with i.d.		
Bodgan and Taylor 1976 US		Social Interactionist/Stigma			

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
Crocker and Quinn 2000 UK	<p>-Present a more sophisticated stigma model.</p> <p>-There are a number of social factors and mediating psycho-logical processes that influence the meaning of the stigma experience.</p>	Social Interactionism/Stigma			-Adds a contextual and dynamic dimension to understanding stigma.

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
<p>Jahado and Markova 2004 UK</p>	<p>-The disability movement and evolving theories of self, “now point to individuals' ability to develop positive identities and to challenge stigmatizing views and social norms.” (p. 719)</p>	<p>Social Interactionism/Stigma</p>	<p>Exploratory study 18 individuals making the transition to the community either from family home or institutions</p>	<p>Goffman/Mead</p>	<p>-Need to understand beliefs about self in relation to others and their social circumstance.</p>

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
<p>Davies and Jenkins 1997 Jenkins 1996, 1998 UK</p>	<p>-The power relationship which structures discourse and experiences of persons with l.d. informs one's construction of self-identity. -The categorical identity of l.d. difficulties has implications for one's relationships with the material world and for the degree of control one experiences.</p>	<p>Structural Determinism/social interactionism</p>	<p>60 individuals with learning difficulties and 59 parents or caregivers</p>	<p>G.H. Mead- the mind exists in social spaces, in mutuality of interaction, between embodied individuals.</p>	<p>-Jenkins- key text <i>Questions of Competence</i> (1998) explores meaning (less) of definition of competency. -He answers the question, is there anything universal to think about in terms of incompetence? He states that "incompetence... is as much an emergent property of social networks and interactional context as it is an endogenous quality of individuals" (p. 227).</p>

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
	<p>-Competency is contextual and therefore fluid.</p> <p>-One needs to look at the power intersections of economic, cultural and educational discourses.</p>				

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
Riddell, Baron and Wilson 2001 UK	<p>-People with disabilities are deprived as a result of their status as a person with l.d difficulties and of aspects of adults' status which are regarded as key aspects of citizenship.</p> <p>-The self has multiple identities and changes with context.</p>	Poststructuralist	30 ethnographic case studies of Scottish men and women with l.d. ages 16 +, over a 6 mo. Visit, w/10 visits each.	Jenkins- see above	<p>-The advantages of middle class social and economic capital are overridden by the negative category of learning difficulties.</p> <p>-Author questions what is the balance between structure and agency in terms of identity.</p>

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
	-There are points of intersection of gender, class, and learning difficulty.				
Baron, Riddel, and Wilson 1999 UK	-There is a marginalization of people with l.d. in the transition from youth to adulthood.	Poststructuralist using development theory.	30 ethnographic case studies of Scottish men and women with l.d. over a 6 mo. Visit, w/10 visits each.-	Hall and performative self, i.e. one's identity is multiple and often contradictory. It is constantly defined and redefined in varying social contexts.	Identity is both strategic and positional.

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
	<p>-Looks at key de- bates about the na- ture of transition and identity forma- tion; psychoanaly- tical model, deve- lopmental, psycho-, moral development, functionalist, struc- turalist, and feminist.</p> <p>-Identity is not a stable entity.</p>				<p>Status of adulthood is evidenced by 4 markers: economic location and independence, domestic independence, formation of intimate personal relationships, development of a personal style.</p>

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
Oliver,1990, 1992, 1996-UK		Social model of disability/Structural determinist			
Gill,Hahn,1995; Roth 1983; Zola 1993; Gill 1997; Hughes and Patterson 1997-US	Gill-Considered identity stages as a group process	Structural Determinist/Minority Group Model			
French and Depoy 2004 US		Structural Determinist/Minority Group Model			

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
Marks 1999, 2002	<p>-We do not look at disability as we do gender and sexuality, because health is considered a private sphere of the body. However, invisibility does not signify unimportance.</p>	Poststructuralist	Foucault	<p>The cultural concept of disability is a “central and powerful organizing principle within contemporary subjectivity and social relationships” (2002, p 11,).</p>	
Field and Hoffman 1997	<p>-Discuss the idea of agency and self-determination</p>	Poststructuralist			

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
Turner 2001	Considers the subjectivity of the “lived body” with the external economic and political structures	Poststructuralist Phenomenologist		Foucault	Although primarily focused on physical disability he considers i.d.- ‘differentness’

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
<p>a. Goodley 1984, 1996, 1998, 200, 2003</p> <p>b. Goodley and Moore 2000</p> <p>c. Goodly and Rapley 2001, 2002 UK</p>	<p>-Suggests politicized narratives that combine stories and actions of disabled people with the socio-political analyses of researchers and activists.</p> <p>-Emphasis on the boundaries of disability politics and disability research.</p>	<p>Poststructuralist</p>	<p>Narrative life course methodology research with self-advocates</p>		<p>Argues for an emancipatory research approach.</p>

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
a. Rapley 2004 b. Rapley et.al 1998 UK		Poststructuralist			
Barnes 2003 UK		Poststructuralist			
a. Chappel 1996, 2000 b. Chappel, Goodley and Lawthorn 2001	b. Application of social model of disability to intellectual disabilities.	a. &b. Structural determinist/Social model of disability	Uses Goodley's research with self-advocates		b. "resilience and resistance are recurring themes throughout the life stories of many people with learning difficulties" (p. 48).

Table 2.2 (continued)

Study ID	Major Thinking	Paradigm	Source of Theory Making	Theoretical Influences	Notes
Szivos-Bach 1993 Szivos and Griffiths 1990	What is the psychological damage of stigma? Those with mild i.d. have the greatest damage to self-esteem.	Positivist	Transition age students with intellectual disabilities		Criticized by Rapley (2004) for essentialism of stigma and group concept assumption Being different treated as 'cancer'
Zigler & Bennett-Gates 1999	Interest is in the motivational determinants of behavior, i.e. learned helplessness	Positivist-development psychology or psychopathology- considers mental retardation as psychopathology	Children with m.r. (sic)	Children with m.r should be understood within the framework of development psychology.	There is a developmental task of self-understanding.

Table 2.3 Review of Empirical Research on Intellectual Disability and Identity in the Social Interactionism/Stigma Paradigm

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Edgerton 1967, 1984,1986, Kennann, 1984, Koegel, 1986;Korbin, 1986, Langess, 1994, Langess & Levine, 1986,McCune, 1973	a. How do persons with mental retardation (sic) perceive the label of mental retardation and try to renegotiate its meaning; what is the construction of social reality of events?	Ethnographic/life history	a. Original group (48) of persons with m.r., followed post-deinstitutionalization, UCLA researchers produced studies over 20 years.	a. Persons with m.r.(sic) would rather label themselves epileptic or “crazy” stigma of m.r. the “ultimate horror” (Edgerton, 1967) Edgerton, (1984) UCLA research “persons ...regard the label, mental retardation, as highly discrediting, and attempt to avoid having it applied to them” (p. 103).	Social Interactionism Goffman/Blumer/ Mead	Classic texts: Edgerton’s (1967) <i>Cloak of Competence</i> ; Langness &Levine (1986) <i>Culture and Retardation : Life Histories</i> Research points to socialized incompetence

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
				There is a systematic denial of access to normal experiences (p. 104).		Whitmore, Langness and Edgerton are the classic works in research on social construction of identity.

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
b. Koegel & Edgerton 1982; (UCLA Socio-Behavioral/Mental Retardation Center) US	b. Koegel &Edgerton-identified reactions to stigma using Goffman’s social stigma theory.		b. Koegel & Edgerton- subsample of African American adults with mild mental retardation who left institution to live in community. Some authors use individual life histories.	b. Persons either denied, avoided or declared that they were ‘handicapped’.	Social Interactionism Goffman/Blumer / Mead	Classic texts: Edgerton’s (1967) <i>Cloak of Competence</i> ; Langness &Levine (1986) <i>Culture and Retardation: Life Histories</i> Research points to socialized incompetence

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
						Whitmore, Langness and Edgerton are the classic works in research on social construction of identity.

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
a. Turner 1980 b. Zeitlin & Turner, 1984, 1988 (UCLA Socio-Behavioral /Mental Retardation Center) US	To what extent does the social stigma of disability affect the individual's self-worth?	Qualitative b. Zeitlin & Turner- followed sample for 18 months	a. Case study of 1 person with m.r. b. 46 adults with m.r. living independently in an urban area (never institutionalized)	Developed psychological constructs for perceiving stigma & coping with stigma: deniers, avoiders, redefiners, and acceptors of stigma: parents primary influence on self-perception, & attitudes toward stigma & adult adjustment: years of independence are positive factors of self-perception.	Social Interactionism Goffman	

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Whitmore 1986 (UCLA Socio-Behavioral/Mental Retardation Center US	Exploratory study on understanding “the retarded” (sic) and how they live the way they do.	Ethnographic/Qualitative research, life history as told by subject. Research collected in early 1960’s and follow up in early 1970’s.	Single subject- Ted Barrett Actual name used per subject’s request. Ted was a member of Edgertons’ <i>Cloak of Competence</i> study.	Ted constructs a social reality of events which to may seem incoherent and sometimes irrelevant. But this qualitative experience portrays Ted as he is, and how he makes his own history.	Social Interactionism	Compares work to work in “third world cultures”. Ted’s story Ted provides grounds for a developmental interpretation of socio-cultural retardation.

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
a. Angrosino 1992	a. What is the relationship b/w social coping strategies of	a. Qualitative, life course	a. 4 deinstitutionalized males	a.&b. Persons with m.r. adopt consistent behavior patterns to cope in community, using metaphors as an adaptive strategy. a. Used Zeitlin's and Turner's typologies of life orientations :	Social Interactionism	The "facts" are not as important as the ways in which the conversations create interactive communicative contexts & world views are revealed.
b. Angrosino 1997 (UCLA Socio-Behavioral/Mental Retardation Center) US	d adults with m.r. (sic) and development of consistent self-image?	b. Qualitative, participant observation (2 yrs.) and interviews with participants	b. 15 Persons (10 men).	Work is similar to Norton's work with nondisabled persons & typologies of life orientations		

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
				blame attribution, acceptance, denial, & tactical dependence status for explanation of strategies for participants b. yearning for recognition as adults significant.		Moving toward positivist paradigm with use of labels/categories; extends work of UCLA to explore metaphors in articulation of self-hood.

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Raymond 2000 UK	If individuals are labeled as disabled they are subject to different treatment; if defined as deviant they will experience devaluation and rejection.	Narrative inquiry; reciprocal and responsive process in interpreting data	2 persons with developmental disabilities over 1 year; 4 taped conversations, each person	Identified 4 themes found earlier by Bodgan & Taylor (1987)- disability is a social construct; there is a stigma attached to label, the stigma produces a self-fulfilling, distancing occurs if labeled as “other”.	Social Interactionism	Stories are about the construction of identity

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Epp 2003 Canadian	<p>What are the self-identified markers of transition to adulthood?</p> <p>Investigated the identity process and sense of integration into adulthood via roles of employment, helping others and personal sense of independence.</p>	Qualitative	Collaborative work with members of Ontario People First Chapter, 1997-1999, with a follow-up in 2003	<p>Discovered 3 themes of adulthood, 1) relative independence in decision-making and lifestyle, 2) social integration and 3) respect</p>	Role theory/Positivist/Stigma	Identity is related to claiming the status of adulthood.

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
<p>a. Jahoda, Markova, Catermole 1989</p> <p>b. Jahoda & Markova 2004 UK</p>	<p>a. Explored subjects' views on stigma and handicap. (p. 103)</p> <p>What is the role of human agency and ability to internalize others' views about oneself that contributes to the development & maintenance of one's self concept.</p>	<p>a. Qualitative</p> <p>b. Qualitative; semi-structured interviews (2 each)</p> <p>Used Edgerton's method of content analysis which produced a summary of views.</p>	<p>a. 12 persons with mild i.d. disabilities transitioning to community from institution, mothers & staff at institution</p> <p>b. 18 adults with mild i.d. disabilities making the transition from either family home (10) or hospital (8) to independent living</p>	<p>a. Identity is influenced by social comparisons made. If lived in or segregated settings they viewed themselves as essentially different. (p. 104)</p> <p>Rejection of label does not deny disability just the label and the attached negative meaning. One manages stigma by distancing from the label and associated stigma.</p>	<p>a. Social Interactionism/ G.H.Mead</p> <p>b. Social Interactionism Goffman/ Mead/ Cooley/Edgerton, uses many of the ideas of Goffman and presentation of self.</p>	<p>a. used categories of same/different from "normal". Study is one of other in relation to dominant culture.</p>

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
	<p>b. 1) Do individuals believe they face prejudice or discrimination & 2) how do they adapt to their social circumstances, & the views of their self they hold or wish to present in relation to stigma.</p>			<p>b. Persons believed that they faced stigmatized treatment & were aware of the stigma associated with i.d..</p>		<p>b. Rejected the Cooley's looking glass theory, "sense of self is not merely a reflection of how one is treated or perceived by significant others." Need opportunities for personal development.</p>

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Whitney-Thomas & Moloney 2001	<p>How do students self-define?</p> <p>What are the influential contextual factors?</p> <p>What are the cognitive processes of self-determination?</p>	<p>Qualitative, semi-structure interviews, participant observations</p>	<p>11 adolescent students (5 w/out disabilities)</p>	<p>Students w/disabilities were more likely to have low self-definition and exp. high struggle. Social support and opportunities for independence are mediating factors in development of sense of selves and ability to cope w/stress. Students learned about self through difficult situations.</p>	<p>Social Interactionism/ Positivism</p>	<p>Criteria of cognitive process of self-determination include future orientation, skills that support decision-making and introspection. Used typologies</p>

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Biklen & Moseley		Qualitative, life history & participant observation	Persons with severe disabilities	Participants construct meaning around patterns within context.	Social Interactionism Berger, Edgerton, Blumer, Becker, Bogdan	

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Azmi, Hatten, Emerson, Caine 1997 UK(Azmi, Hatten, Emerson, & Caine, 1997)	How does self-esteem intersect with disability and ethnic identity?	Qualitative-content analysis of structured interviews	Adolescents and adults (21) with intellectual disabilities in the English South Asian communities	Ethnic identity is stronger than identification with a disability. Those w/strong and positive sense of ethnic and racial identity are generally satisfied with home and family. Experienced pervasive racism and stigma in all areas of their lives. 15/16 identified primarily as Asian or Indian, one identified primarily in terms of disability.	Social Interactionism	Assumed that identification with disability is a negative.

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Bogdan 1982 US	Labels are not useful to understanding people's lives.	Qualitative	2 persons with intellectual disabilities	The concept of m.r.(sic)is neither meaningful nor useful. It is socially created. In study, interviewee does not define himself as mentally retarded, "who would want to?"	Social Interactionism	Criticizes Edgerton that he does not challenge the usefulness of the concept of mental retardation. When we abandon labels we stop blaming person & shift gaze to society & service systems.

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Craig, J., Craig, F. Withers, Hatton, Limb 2002 UK	Explore “the relationship that the people with an intellectual disability have with their intellectually disabled identity and examine the influence services for people with intellectual disabilities have on this relationship” (p. 63).	Mixed method, information collected by 1) audit of 92 referrals to community psychology service for persons with disabilities, 2) 6 people with i.d. in a service-users focus group, discussion about experiences in being involved in services 3) 31 surveys of service providers.	6 people with i.d. 92 audits, 31 surveys	According to service users persons with i.d. are uncomfortable talking about disabled identity and tend to portray oneself as non-disabled, they distance self from other service users; there is an unmet service need for persons to come to terms with identity.	Social Interactionism	There is a need for careful consideration of the ways in

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
						<p>which this identity is managed by service-providers. (p. 61) As a result of negative social evaluations people with labels may either deny or make no reference to their label.</p>

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Rapley, Kiernan, Antaki 1998 UK	Challenge the notion of an “all-embracing ‘toxic’ identity.			Understanding that self is more fluid & dynamic in young people with i.d.. They can avow or disavow identity in relation to current context. Youth tended to orient themselves to being ordinary or to pass.	Social Interactionism	People may manage their identity by mobilizing & acknowledging the views of others
Rubin& Heal 1996	What is the long term impact of institutionalization on identity?	Qualitative, revisited adults after 10 yrs. Living in own apt.	10 adults with developmental disabilities who had been institutionalized			Quality of life primarily

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Beart 2004 UK(Beart, Hardy, & Buchan, 2004)	The generation of a model of impact of self-advocacy group membership on individual's sense of self	Grounded theory	8 adults with learning disabilities who belong to self-advocacy group	Although they belonged to self-advocacy group 50% did not identify with such. All struggled with the meaning of the label.	Social interactionism	

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Dowse 2008(Dowse, 2008) UK	Study of people w/ i.d. in self- advocacy org. (AU and Britain) Process of connecting self- advocate as a disability identity and self- advocacy as disability culture. How persons created their own forms of knowledge and shape themselves as subjects through talk and action.	Participatory action	Persons with intellectual disabilities who are active in self- advocacy. Details of sample not given.	(Findings not reported in conference proceedings)	Social Interactionism	

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Knox &Hickson 2001 AU	Explored the meaning of close friendship	Qualitative, parti-cipatory approach with structured in-terviews. Ground-ed approach.	4 people with intellectual disabilities		Social Interactionism/ Phenomenolo-gical	

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Davies & Jenkins 1997 UK	To what degree is this categorical identity incorporated into individual self-identity? Do persons defined as learning disabled understand society's label and do they apply it to themselves? Explored self-identity formation in response to social interactions	Mixed methodologies, structured questions, rating of knowledge	60 adults (ages 18-26 years) of different abilities and their families or carers over 3 yrs	Persons with disabilities live w/ incongruence of a categorical identity as someone w/ a learning difficulty & their self-identity. Few incorporated the categorical identity into their self-identity;	Social Interactionism/ Mead; Post structuralist	Label of disability is a master status and takes precedence over other social identities. Identity is formed in response to social interactions

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
				<p>almost all incorporated the experiential relationship of others exercising power over them. 42% did not know meaning of learning disabilities, mental handicap; 28% gave definition which only included themselves, 13% gave vague or partial answer.</p>		<p>There is a distinction b/w understanding one's own social identity of having a learning disability at a verbal level and understanding it at an emotional level; the acceptance of label to self-identity can be an emotionally painful experience.</p>

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Harris 1995 US				Persons with intellectual disabilities do not use label because they are trying to deny it.	Social Interactionism	

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
<p>a. Finlay & Lyons 1998</p> <p>b. Finlay & Lyons 2000</p> <p>c. Finlay, Rutland & Shotton 2003 UK</p>		<p>a., b. &c.</p> <p>Qualitative</p>	<p>b. 33 persons with Down syndrome</p> <p>c. two focus groups of 12 participants, ages 21-42.</p>	<p>a. No relationship b/w label acceptance and self-esteem. Those who didn't accept their label felt more competent.</p> <p>b. One may construct positive identity through the social worlds that they describe based on choice of social comparisons and categorizations</p> <p>c. themes: positive relationships, obstacles to social goals, negative evaluations and supporting others.</p>	<p>Social Interactionism</p>	<p>What you think of yourself depends upon who you compare yourself to. Authors rejected globally disabled identity. Label is a social construction</p>

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Taylor 2000		Qualitative, ethnographic			Social Interactionism	
Higgins, Raskind, Goldberg, & Herman, 2002 US	To understand and describe students' life-span experiences so that generalizations, implications, and recommendations could be made for all persons with LD" (p.3) Looked at acceptance of l.d. over time.	Mixed methods , 20 year longitudinal study	41 individuals, in mid-30's with learning disabilities. Attended institution as children	There are distinct stages of 'coming to terms' w/ social/emotional impact being labeled. 1) awareness of differentness, 2) labeling event, 3) understanding/ negotiating the label; 4) compartment alizing & transformation.	Social interactionism/ Goffman's stigma theory and applies a stage development of acceptance of a disability.	Research strategies focused on symbolic, shared systems, study persons one at a time, and regard participants as 'expert consultants'.

Table 2.3 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
						Disability is considered a loss and it requires an acceptance, denial and redefining the label on how to accept the deficit.
<p>* i.d. refers to intellectual disability, l.d refers to learning disability; U.K. reference to learning disability or is synonymous with U.S. intellectual disability/mental retardation</p>						

Table 2.4 Review of Empirical Research on Intellectual Disability and Identity in the Structural Determinist Paradigm

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
Develieger & Trach 1999 US	Examined the process of mediation during life transition of high school to employment	Ethnographic, life history interviews with focal persons	High school students with mild m.r. and significant others (teachers, coworkers, family, friends)	Mediation is anticipated by critical life events. IEP is important tool during this process	Structural Determinist, also cites Edgerton	Mediation is the social process that integrates a person's life transition in the context of a social network.

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
Chappel, Goodley &Lawthom 2001 UK	Explores social model of disability and significance for people w/l.d. Examines why l.d.researchers have not used the social model to understand experiences of people with l.d.	Ethnographic study of self-advocacy groups, uses Goodley’s (2000) previous research	Persons with cognitive disabilities	"It is clear that resilience and resistance are recurring themes throughout the life stories of many people with learning difficulties" (p. 48).	Structural determinist/ Social model of disability	

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
Olney & Kim 2001	The stage process is not about acceptance of disability but rather adjustment of attitudes to disability	Focus group uses comparison groups	16 college students with learning disabilities, psychiatric diagnosis, and brain trauma	Formation of identity is a complex process. Development of positive self-concept includes management of perception of others and implications that disability has on one's own life.	Structural determinist/post-structural	The process is related to how one makes sense of one's own situation and the meaning one attributes to one's disability status. *Not specifically intellectual disability

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
Jones 1992 Canada	To develop a clearer understanding of the kinds of relationships, kinships and cultural signifiers that developed in the institution and beyond.	Qualitative, made videotapes explaining situations and experiences at the institution. Group collaboration, no prepared questions	4 adults with i.d., ages 35-67., who knew each other. Came to Huronia Regional Centre at age 4 & left 10-20 years later. All working in competitive jobs.	Individual's self identity reflected a sense of self in opposition and a sense of support of the facility that was their 'home'. (p. 340) "They were not simply products of the institution, but active participants in developing their sense of self as social/cultural	Poststructuralist/ Foucault Goffman	Examined the "subject" in relationship to institution rather than examining the institution. Stories are a backdrop for understanding relationships

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
				<p>beings, contextualized within their collective institutional experiences." (p. 340).</p> <p>Themes of loss of family, feel-like an orphan.</p>		<p>of power and dominance w/in the institution and their participation w/in and outside of those cultural forces." (p. 341).</p>

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
Berne, McArthur, Gaffney 2008 New Zealand	Ethnographic study of the impact of school experiences on identity, views of students on salience of impairment and disability in their perceptions of self and others.	Ethnographic study, observations and semi-structured interviews w/ students, parents and school staff	9 students, ages 11-14 with disabilities	Students try for inclusion and equality with school peers, while trying to meet needs related to impairment. This conflicting processes require a shift b/w multiple identities and representation of self depending on context.	Structural determinism ; geographies of youth identity & sociology of childhood	There is a need to counteract imposed master identities and challenge disabling discourses at school that impact self-identity and positive self-esteem.

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
				<p>Students use range of approaches to (re)negotiate positive sense of self, showing agency and ability to resist various forms of oppression. These experiences have a negative psycho-emotional impact.</p>		<p>This will require schools to be more actively engaged with disability issues, and to provide practical and psycho-emotional supports for disabled students.</p>

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
Cunningham & Glenn 2004 UK	Investigated the awareness of difference and stigma, within a social-cognitive stage framework.	Mixed method; interviews, photographs, standardized test	77 young adults with Down Syndrome and parents	Social-cognitive developmental awareness of difference approximated the verbal mental age. No associations were found b/w measures of self-esteem and levels of awareness and chronological age. All had high self-esteem and awareness of DS and disability. For the majority disability did not appear as a major issue.	Structural determinism/ social-cognitive model for development of self-awareness of disability	Beginning approx. at mental age of 8 yrs. old social comparisons and categories developed.

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
						<p>Sequence: emergence of self-understanding, self-evaluation, social category-ization and awareness of disability and self-categorization.</p> <p>Research supports the developmental sequence model in disability.</p>

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
Rapley 2004 UK	Focused on the interactional production of incompetence b/w the persons with the disability and the interviewer	Qualitative, ethnomethodology; conversation analysis; analysis of videotape and interaction between staff & residents.	Videotaped & written transcripts of data collected from group homes for adults with moderate to mild i.d.	Detailed the psychological concepts and descriptors of “passing” and “denial of disability” and reframed as related to the competency of those described as intellectually disabled.	Poststructuralist Foucaultian perspective Social interactionism	Frequently cited disability studies theorist, <i>The Social Construction of Intellectual Disability</i> , refers to his work as discursive psychology.

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
Riddell, Baron & Wilson 2001 UK/Scotland-	To what extent are people involved in the voluntary construction of social identity? To	Ethnographic case studies	30 men & women with intellectual disabilities, 10 visits each over 6 months	All persons were deprived of their adult citizenship status, including	Poststructuralist Marxist model	Self is viewed as having multiple identities and changing with the context.

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
	<p>what extent are their lives shaped by social structures of gender, race, disability, and social class? Explored the differences and commonalities of each individual.</p>			<p>civil, economic, and political rights as a result of their status as a person with learning difficulties. Points of intersections are gender, class and learning difficulty. Middle class and social and economic capital are overridden by learning difficulties status.</p>		<p>Looked at the balance between structure and agency, considered key issues in identity.</p>

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
Baron, Riddell, Wilson 1999 UK	Construction of identity in terms of a transition from youth to adult and marginalization of people with learning disabilities. Questions stability of self and if adulthood	Qualitative ethnographic study	30 case studies of persons with Down Syndrome-transition group- (16-early 20 yrs), post-transition (late 20's-mid 30's), group over 40. Gender and ethnic balance as well.	All persons of all ages were treated as 'eternal children'. Participants did not refer to selves as learning disabled. Disability is a master category.	Post structuralist using developmental theory regarding identity.	4 key markers of adulthood in relationship to persons with i.d. 1. economic location and independence, 2. domestic independence, 3. formation of intimate personal relationship,

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
	<p>delayed or nonexistent for persons with intellectual disabilities. Looks at the construction and is negotiation of identity</p>					<p>4. development of personal style. Authors raise question of applicability of social model for intellectual disability. In post-industrialization there is not a stable identity because of extended time.</p>

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
Seale, 2001 UK	Exploration of identity formation through analysis of web pages	Qualitative, analyzed for thematic content, form, language	Web pages of 20 adults with Down Syndrome (DS)	Persons with i.d. manage their identities and vary them according to context, identity is not static, may not include disabilities. Web pages allows the potential for expression of multiple identities. Themes of content of web page: this is me, I am a member of a community, family and the DS community.	Social Interactionist Goffman/ Poststruturalist	With the internet one is valued for what one thinks or communicates.

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
Rubin, Bilken, et al. 2001	What are the multiple identities of a person with severe disabilities?	Collaborative narrative research	Co-researcher, labeled severely retarded in early life. She is now labeled now as having autism and a communication disability.	Key themes related to multiple identities : freedom, participation, identity and agency. There is a cultural production to the interpretation of the performance of the body.	Poststructuralist	

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
Watson 2002 UK/Scottish	Do people with disabilities know who they are? Looks at factors of knowledge of impairment, discrimination. Who to they ontologically believe themselves to be?	Qualitative	28 persons with disabilities (14 men)	Majority did not see disability as important to sense of identity. "Self is a product of self-determination, autonomy and choice" (p. 515). Persons restructure the idea of normality. This is achieved in part by constructing a narrative identity that allows for a separation of body image and self-identity (p. 515).	Poststructuralist A.Giddens, C. Taylor	Author does not believe that there is a group identity. Self is not about difference; it is about what one can do. The self is universal, something shared by all. We learn who we are by symbols and language.

Table 2.4 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm Primary Theorist	Notes
* i.d. refers to intellectual disability, U.K. reference to learning disability is synonymous with U.S. intellectual disability/mental retardation.						

Table 2.5 Review of Empirical Research of Identity and Intellectual Disabilities in the Positivist Paradigm

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Schurr, Joiner, & Towne 1970 US	Literature review of articles focused on self-concept and mental retardation	Literature review; organized around 3 themes: general studies of persons with mental retardation (sic) self-concept;	32 quantitative peer reviewed journal articles	1) Studies used instruments to measure self-attitude and adjustment. Findings are equivocal and generalizations can not be made about the mentally retarded's (sic) self-concept.	Positivist, Identity development is a result of deficits in "normal development". Disability is considered a maladjustment from the normal or typical.	Author acknowledges the need to overcome the biases of self-concept scales and the researchers and greater attention should be given "to recoding and classifying spontaneous self-referent statements." (p. 42).

Table 2.5 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Schurr, Joiner, & Towne 1970 US (cont)	Literature review of articles focused on self-concept and mental retardation	The effects of a special class placement on self-esteem; the relationship b/w school achievement and self-concept	32 quantitative peer reviewed journal articles	2) Mixed results found regarding self-esteem of those special education students in “low ability” and “high ability” groups, through use of self-concept instruments. 3) Self-concept and school achievement: used achievement and personality tests.	Positivist, Identity development is a result of deficits in “normal development”. Disability is considered a maladjustment from the normal or typical.	Author acknowledges the need to overcome the biases of self-concept scales and the researchers and greater attention should be given “to recoding and classifying spontaneous self-referent statements.” (p. 42).

Table 2.5 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Frison, Wallender, Browne 1998	What are resiliency factors for African Am. Youth with mild m.r. (sic)? Focused on 3 factors that may foster resilience, personal-ethnic identity, social-intergenerational support and community-church support.	Quantitative Used ethnic identity measures, support measures and adolescent risk factors tools	147 African American adolescents, ages 13-17	Found that positive ethnic identity was a possible mechanism for fostering positive outcomes for teens with mental retardation.	Positivist	Authors did not consider the possibility of a positive disability identity.

Table 2.5 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
	Investigated protective role of cultural factors rather than examining their associations with outcome measures.					

Table 2.5 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Gibbons 1985					Positivist	Criticized by social interactionist researchers, Finlay, Jahoda
Dagnan &Sanhu 1999	Focus on social comparison, self-esteem and depression			The number of positive social roles that persons have may act as a buffer against the emotional damage of stigma.	Positivist	.

Table 2.5 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Kaufman 1986 US	Explores relationship of mother with adult daughter who is i.d.	Qualitative, single ethnographic study	Mother writing about her relationship with daughter	Upon reflecting on daughter's desire to be part of world, mother reframes definition of success.	Positivist- Role theory, uses adult typical roles for comparison purposes.	
Szivos & Griffith 1990 UK				Those with m.r. (sic) who have not accepted label and accompanying stigmatization will be psychologically damaged.	Social Interactionist/Positivist-essentialist	Criticized by Rapley, Post-structuralist.

Table 2.5 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/Primary Theorist	Notes
Szivos-Bach 1993 UK	Stigma is an important component of the subjective experience of persons with mental retardation.	Qualitative	Young adults with mild mental retardation	Persons with mild m.r. (sic) who perceived the most stigma had the lowest self-esteem. Both stigma and social comparisons contribute to the definition of the person's status as normal/not normal	Positivist	Criticized by Rapley, Post-structuralist.

Table 2.6 Review of Empirical Research of Identity and Intellectual Disabilities in the Phenomenologist Paradigm

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/ Primary Theorist	Notes
Knox, Mok, Parmenter 2000 AU	Understanding disability as a personal experience	Qualitative, collaborative and grounded theory; emancipatory	6 persons with i.d. , were interviewed over extended period.	Focus on article is collaborative process with interviewee.	Phenomenologist	
Knox & Hixson 2001 AU	Meaning of close friendships	Grounded theory, unstructured interviews, participatory approach	4 persons with intellectual disabilities		Phenomenologist. Social interactionist	

Table 2.6 (continued)

Study ID	Study Focus	Methods	Participants	Findings	Paradigm/ Primary Theorist	Notes
O'Byrne 2001 US	What does it mean to be human in a particular way?	Hermeneutical psychology approach	1 person with mild intellectual disability	Emotional- social disability is a significant aspect of mild i.d. The self is not only a container of social exper- iences but rather the self emerges from the relation- ships of social and biological world.	Phenomen ologist/ social interaction ist	Dissertation

Table 2.7 Summary of Historical Eras of Intellectual Disability

Time Period	Prevailing Societal View	Label	Society's solution	Wolfensberger's Role Classification-Roles may be cumulative throughout history	Significant factors/conditions
1700's	Puritan-truth and beauty All those not deemed worthy of goodness were lumped together	Lunatic	House of Corrections Located in city	Subhuman	Strong religious orientation, persons deemed as good or bad from birth

Table 2.7 (continued)

Time Period	Prevailing Societal View	Label	Society's solution	Wolfensberger's Role Classification-Roles may be cumulative throughout history	Significant factors/conditions
1800's-1840's	Result of personal failings of self or family, moral flaw		Alms Houses Local problem	Sick Role	Systematic individualization and medicalization of body and mind. Persons with apparent disabilities excluded from mainstream life. (Armstrong, 1983; Foucault, 1975; Rapley,20004)
1840's-1860's			Schools (1850's), educational model Location: First school located in heart of city	Sick Role	Emerged as social problem. Residential: (1850s) Institutions were training schools where deviant could be less deviant

Table 2.7 (continued)

Time Period	Prevailing Societal View	Label	Society's solution	Wolfensberger's Role Classification-Roles may be cumulative throughout history	Significant factors/conditions
1860's-1890's	Pity Failure to become normal was fault of person, they were degenerates	Idiots	Professionals take control	Object of pity	Post civil-war, institutions became political in nature. Training "idiots" deemed a failure and value of integration replaced with (1880s) pity for 'untrainables', the 'idiots'. Protective care for 'idiots'. Distinguished between who could and could not learn. Those that could be cured moved back, those not curable left behind. 1880's farm colonies.

Table 2.7 (continued)

Time Period	Prevailing Societal View	Label	Society's solution	Wolfensberger's Role Classification-Roles may be cumulative throughout history	Significant factors/conditions
1890's-1920's	<p>1930's- "facts" changed and identification and training, segregation were seen as key</p> <p>Residential- huge growth of institutions, in rural areas, seen as benevolent protection</p>	Idiots	Asylums, custodial care Control- Sterilization, segregation- could prevent mr	Burden of Charity Holy Innocent	<p>Growth of institutions, anti-immigration, institutions formerly training schools became warehouses</p> <p>Protective care, burden of charity, holy innocents, eternal children, national marriage law to prohibit marriage of feeble-minded.</p>

Table 2.7 (continued)

Time Period	Prevailing Societal View	Label	Society's solution	Wolfensberger's Role Classification-Roles may be cumulative throughout history	Significant factors/conditions
1908-1924	Menace of the feeble-minded	Feeble-minded, degenerates	Eugenics	Subhuman/Menace	Part of societal fear of the other, the menace, anti-immigration. Menace mentality lingered for 50 years in professional circles and public consciousness

Table 2.7 (continued)

Time Period	Prevailing Societal View	Label	Society's solution	Wolfensberger's Role Classification-Roles may be cumulative throughout history	Significant factors/conditions
1920	Belief in scientific evidence Use of "science" to validate difference-	Inmate became patient, moron or retardate or mental deficient	Sterilization	Subhuman/Menace	Society continued to fear that "defects" would outnumber "normal people" state run institutions. Intelligence testing "proved" the existence of morons or retardates, justified the larger institutions as more efficient, more scientific. Few activities or stimulation in the institutions. Effort to isolate and control, staff stayed behind windows and doors.

Table 2.7 (continued)

Time Period	Prevailing Societal View	Label	Society's solution	Wolfensberger's Role Classification-Roles may be cumulative throughout history	Significant factors/conditions
1950's	Paternal; For the good of the child and society		Medical model	Object of pity/Sick Role	Scientific evidence changed scoring of mental retardation-people lower than 83 were mentally retarded. Parents urged to institutionalize child for everyone's benefit. Mildly retarded were kept in institutions to serve as unpaid labor. Community special education classes were dumping grounds.

Table 2.7 (continued)

Time Period	Prevailing Societal View	Label	Society's solution	Wolfensberger's Role Classification-Roles may be cumulative throughout history	Significant factors/conditions
1960's			Deinstitutionalization	Sick Role/developing Person	Civil rights and social reform occurring in society. JFKennedy established the President's Committee on Mental Retardation. More exposes- Christmas in Purgatory (1966) Largest institution for 600 now held 2,000 patients.

Table 2.7 (continued)

Time Period	Prevailing Societal View	Label	Society's solution	Wolfensberger's Role Classification-Roles may be cumulative throughout history	Significant factors/conditions
1970		Developmentally disabled	<ul style="list-style-type: none"> • Least Restrictive Alternative, Normalization, Social role valorization • Treatment Centers • Sheltered Workshops 	Sick Role/Developing Person	Change of IQ scoring mental retarded score 63 or less on IQ test. (Millions had label removed.) Laws expanded rights of disabled: Education for All Handicapped Children (1975), The Developmentally Disabled Assistance and Bill of Rights Act (1975), Rehabilitation Act (1973)

Table 2.7 (continued)

Time Period	Prevailing Societal View	Label	Society's solution	Wolfensberger's Role Classification-Roles may be cumulative throughout history	Significant factors/conditions
1980 Mid-1980's	Dignity of risk		Deinstitutionalization, Normalization, Social role valorization, Social skills building	Developing Person	Push toward normality Civil-rights base
1990	Lacking competency, defective intelligence, Individual growth and potential Self-advocacy	Intellectual disability	Supportive living	Sick Role; Developing Person	Civil and human rights issue Disability is shaped by the environment (Gill, 1997; Hahn, 1997)

Table 2.7 (continued)

Time Period	Prevailing Societal View	Label	Society's solution	Wolfensberger's Role Classification-Roles may be cumulative throughout history	Significant factors/conditions
2000-present	Self-advocacy				Civil and human rights issue, Renaming-department of mental retardation to developmental disabilities.

Table 2.8 Identity Statuses and Developmental Progress (Marcia, 1993)

Diffused -Has not considered the choices and therefore commitment made	Moratorium -Does not experience alternatives
Foreclosed -Accepts commitment without experiences alternative	Achieved -Considered and made choices

Table 2.9 Management of Identity Status by Crisis and Commitment (Marcia, 1993)

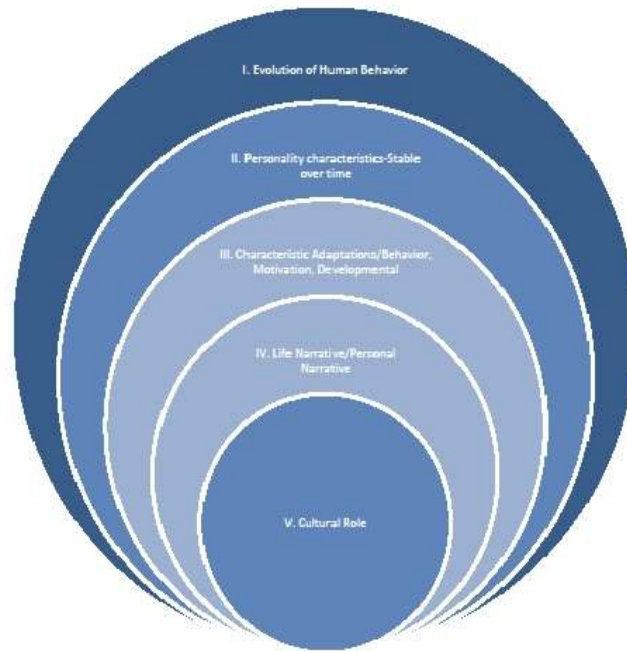
Crisis			
Commitment	No		Yes
	No	Diffused	Moratorium
	Yes	Foreclosure	Achieved

Table 2.10 Identity Types and Identity Processes

Identity Process	Identity Formation/Development	Identity Construction	Identity Negotiation
Significant Question	How do I fit in the world?	Who/what are my influences?	What is the political nature of my personal and social identifications?
Identity Type	Personal Identity	Social Identity Collective Identity	Self-Identity
Statement of identity Definition	This is who I am because of how I make sense of my social and internal world. Intersection of social and psychological spaces	This is who I think/feel I am because of others Outcome of an identification of self by other	This is who I am when I tell my story State of being distinct from all others Reflexively understood by the person in terms of his/her own story

Figure 2.1 Making Psychological Sense of the Individual Life

Figure 2.1, Making Psychological Sense of the Individual Life



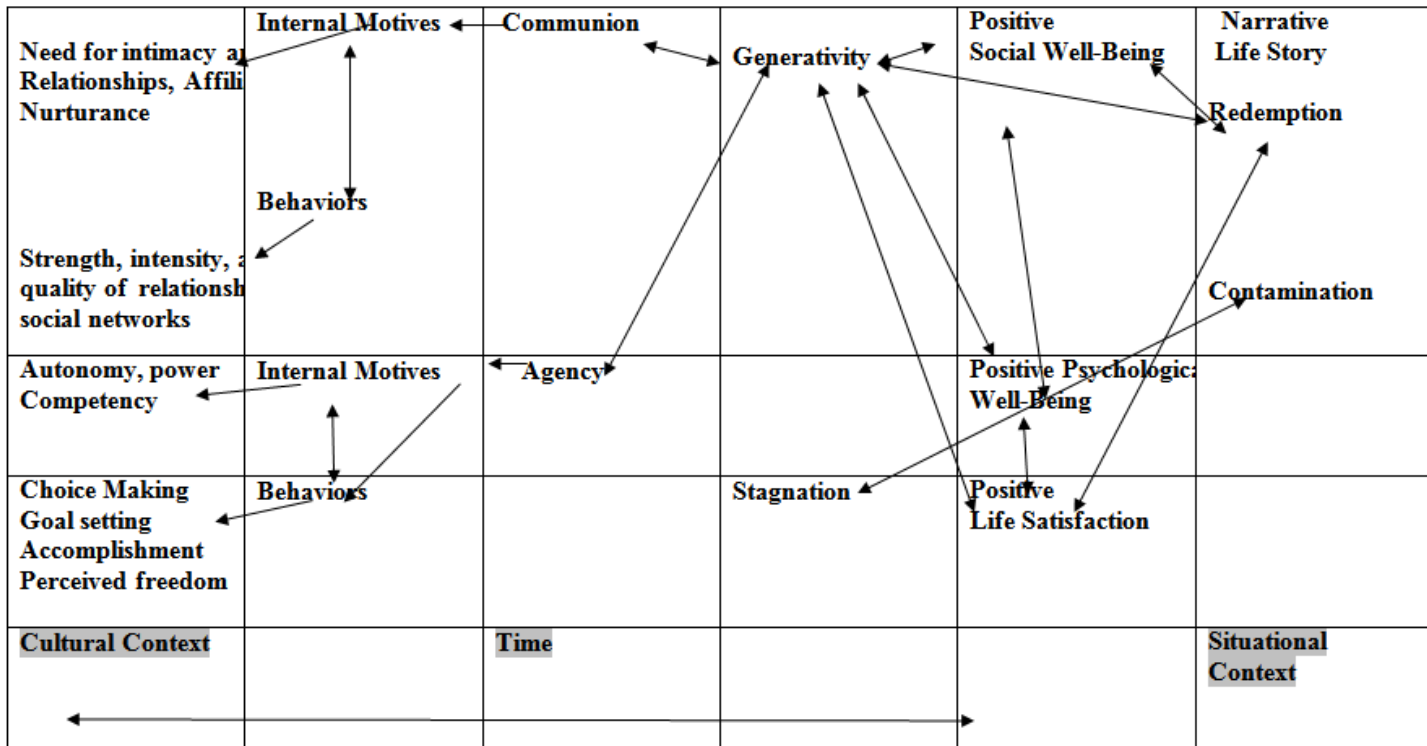
McAdams & Pals, 2006

Figure 2.2 Application of McAdams' identity making process to persons with intellectual disabilities

Principle	Level of meaning	Placement of meaning	Key Concepts
Three Characteristic Adaptations	Broader view of identity as contextualized to historical time, personal situation and social roles	Attitudinal shift promoting self- empowerment and advocacy , challenging past assumptions of devalued social role for persons with intellectual disabilities Creates a present tension due to shift in hegemony	Motivational, social-cognitive and developmental concerns <i>Doing</i> side of personality; goal directed; incorporates the developmental motivations and behaviors of generativity, agency and communion.
Four Life Narratives and Challenge of Modern Identity	Personal meaning	Personal meaning is explored through the use of life story and process of person centered planning	Personal agency ("nothing about me without me") communion and inclusion as a full citizen. How are these concepts incorporated in one's personal identity?

Figure 2.3 Linkages between McAdams Life Story Concepts

Figure 2.3 Linkages between McAdams Life Story Concepts



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Chapter 3

Methodology

This chapter details the methodological approach for this dissertation, investigating the *Identity Making Process of Individuals with Mild Intellectual Disabilities*. Included in this chapter are sections addressing 1) the design of the research, 2) the quantitative and qualitative measurements chosen for and adapted for the needs of the study sample, i.e. person's with mild intellectual disabilities, 3) the study sample, 4) data collection and 5) data analysis. The research questions presented in Chapter 1 are reiterated to foreground the discussion of study methods, data collection, data analysis and data presentation.

Design

This research is an original data analysis through the use of combined qualitative narrative and quantitative approaches. Triangulation in this research includes the use of three standardized instruments and the qualitative life story interview format. The two methods inform one another to best explore the identity making process of individuals with mild intellectual disabilities.

Life Story Approach

The Life Story is a mixed methods approach combining a qualitative life story interview, and four quantitative measures consisting of two scaled instruments (Satisfaction with Life Scale and Loyola Generativity Scale), one checklist (Generative Behavior Checklist) and coding systems for the Life Story Interview. (See Appendix A: Life Story Interview (adapted), Appendix B: Satisfaction with Life Scale, Appendix C: Loyola Generativity Scale, Appendix D: Generative Behavior Checklist (Adapted), Appendix E: Coding System for Themes of Agency and Communion, Appendix F: Coding System for Redemption Sequences, Appendix G: Coding System for Contamination Sequences.) McAdams (2006b) identifies the life approach as acknowledging the strengths of persons as storytellers. His life story format emphasizes that life stories give a person an identity, and provides meaning and purpose to one's life. The quantitative measures complement the narrative approach, allowing the researcher to check the narrative story and its resultant themes of agency and communion and generativity/stagnation with a scaled reliable and valid instrument and checklist. (McAdams & de St. Aubin, 1992; McAdams, Hart & Maruna, 1998). The Satisfaction with Life Scale, a more global assessment of

mental health and quality of life, associates positively with generativity and generative concern. (de St. Aubin & McAdams, 1995; Grossbaum & Bates, 2002)

Narrative Inquiry

Narrative inquiry, an approach that provides the retrospective accounts of persons about their experiences of self-definition or defining, is an excellent fit for the social work perspective. Social work emphasizes understanding each person for one's individual human meaning making. The strength-based approach encourages examining the larger contextual view of time, place and persons and appreciating one's existence as a continuous experience, and not as discrete problems to be solved. (Fraser, 2004)

Similar to social work's person centered approach, narrative inquiry considers the person telling the story as the expert on the topic at hand. With narrative inquiry, research analysis examines multiple stories for connections between individuals and appreciates the uniqueness of each individual story (Stuhlmiller, 2001). The qualitative nature of the narrative inquiry allows the researcher to uncover insights, exceptionalities and nuances that are not visible at the group level (Phinney, 2000).

The methodology of narrative research has a firm foundation in the social science and educational fields. (Denzin, 1978, 1989, 1997; Denzin & Lincoln, 2000, 1994; Geertz, 1974; Giele & Elder, 1998; Glazer & Strauss, 1967; Josselson et al., 2003; Miles & Huberman, 1994; Mishler, 1986a, 1986b; Rosenthal, 1993; Rosenwald & Ochberg, 1992; A. L. Strauss & Corbin, 1994; S. J. Taylor & Bogdan, 1984) Significant to practice, Clark (2010) provides clinical application of life story narrative, providing the mental health field with theoretically anchored practice methods.

This study, using a life story method, begins with the quest for understanding the personal meaning of identity formation in persons with mild intellectual disabilities. Current qualitative research methodology adheres to the principle of including the subject's voice. This quest leads to the qualitative approach that emphasizes mining narrative data for meaning.

This narrative inquiry allows for the subjective experiences or phenomenology of individuals to hold center stage for review and analysis. Through the life stories one can witness the person and the world as mutually constitutive in identity making. The story drives the analysis and the emergence of themes. As outsiders we do not know how an individual's life is experienced at the time or how one might have reconstructed the experiences in order to fit in

one's life narrative. It is the researcher's challenge to capture the perceptions of the individual in how the person constructs and understands the world and subsequently, one's own identity. Rosenwald (2003) believes that narrative study poses two questions, *what is the person's life* and *how did he or she become this kind of person?* Providing illustration of this O'Byrne (2001), in her qualitative study exploring the lives of persons with borderline cognitive deficits, raises the question *what does it mean to be a human being in this particular way.*

Northwestern University's Foley Center for the Study of Lives Life Story Approach

This dissertation draws heavily on the extensive work of Northwestern University's Foley Center for the Study of Lives. The Foley Center, led by Dan McAdams, is an interdisciplinary research project committed to studying psychological and social development in the adult years... Foley Center research focuses on prosocial aspects of development as generativity, social commitment, altruism, life-long learning and the development of self-understanding across the adult life course" (<http://www.sesp.northwestern.edu/foley/>).

Significant to the field of personality psychology is McAdams' and Pals' (2006) framework of 5 overarching principles for conceptualizing personality and identity making. They not only offer a conceptual framework to understanding "psychological individuality constructed in response to situated tasks and human need to make meaning in culture" (p.204) but a research methodology to study the process of the individual.

McAdams' and Pals' (2006) Principle 5 considers the impact of culture on the psychological self.

Culture exerts different effects on different levels of personality: It exerts a modest effect on the phenotypic expression of traits; it shows a stronger impact on the content and timing of characteristic adaptations; and it reveals its deepest and most profound influence on life stories, essentially providing a menu of themes, images, and plots for the psychosocial construction of narrative identity (p. 211).

McAdams' and Pals' (2006) Principle 4 suggests a research methodology to study this process, which acknowledges the fluidity, continuous production and interactional nature of identity making. Principle 4 states that:

(B)eyond dispositional traits and characteristic adaptations, human lives vary with respect to the integrative life stories, or personal narratives, that individuals construct to make

meaning and identity in the modern world. ... Narrative approaches to personality suggest that human beings construe their lives as ongoing stories and that these stories help to shape behavior, establish identity, and integrate individuals into modern social life (p. 209).

McAdams and Pals' Principle 3 emphasizes the *doing side* of personality, the motivation, social learning, coping mechanisms and human developmental challenges. This principle also incorporates the developmental motivations and behaviors of generativity, agency and communion. McAdams' Life Story Interview, the Generative Behavior Checklist and the Loyola Generativity Checklist capture the *doing side* of every day behavior as well as the motivations of generativity, agency and communion.

These three Principles reflect my interest in 1) exploring the concepts of redemption, contamination, agency, communion and generativity as they pertain to identity making, 2) employing a narrative research approach to explore individuals' life stories and their personal meaning to the story, 3) recognizing the fluidity and interactional nature between external and internal factors in identity making, based on context and one's personality characteristics and 4) exploring the socio-cultural influences on individuals' life stories. The Foley Center for the Study of Lives approach and specifically much of McAdams' work on identity significantly informs this study, along with the narrative inquiry approach to understanding individuals' lives informs this research. The research instruments developed at the Foley Center provide tools to explore these conceptual relationships evidenced in the interviewees' stories. The life story interview offers an iteration of the broader life story methodology. Figure 3.1 at the end of this chapter graphically depicts the process of matching research tools to the research questions.

Measurements

Adaptation to Interviewees' Potential Cognitive and Literacy Challenges

Based on pre-data collection results which included feedback from two individuals with intellectual disabilities and a focus group composed of advocates with disabilities, minor adaptations were made to the Loyola Generativity Scale, the Satisfaction with Life Scale and the Life Story Interview to ensure a more reliable response to the quantitative and qualitative tools. Additionally, use of the Flesch-Kincaid Reading Scale (www.readability-score.com) provided information regarding the reading capacity necessary for reading the Generative Behavior Checklist, the Satisfaction with Life Scale and the Loyola Generativity Scale. Reading levels ranged from a high of grade 8.6 for the Generative Behavior Checklist to a low of grade 5.3 for the adaptive Loyola Generativity Scale. These instruments as well as the Life Story interview (which measured grade 5.6) were read to the interviewee allowing for simpler explanation of unclear terms or concepts. Ancillary material developed for this research, including the Brief Assessment for Capacity to Consent, the Consent Form, the Pretest for the Likert Scale and the recruitment talk were written between grades 2.6 and 6.4.

Confirming my discovery of the challenges of using quantitative instruments with persons with intellectual disabilities, Hartley and MacLean (2006) found in their review of 51 published studies (1979-2005) of reliability and validity of Likert-type scales for people with intellectual disability that, “on average, response rates for Likert-type scales are comparable with, and often higher than, those reported for yes/no, either/or and open-ended” (p. 815). Two-thirds of the studies reporting on reliability and validity for Likert-types scales used with adolescents and adults with borderline IQ to mild ID received a rating of moderate to strong internal consistency, test-retest reliability, concurrent validity, and convergent validity (p. 818).

Distinguishing between levels of intellectual disabilities, the authors found that for adults with borderline IQ to mild ID the inclusion “of pictorial representation of response alternates, a single set of one or two word responses, descriptors, clarifying questions and pretests” (p. 814) increased the ability of individuals to accurately respond to Likert-type scales.

I incorporated several of Hartley and MacLean’s recommendations into this research. 1) When there was an initial question regarding cognitive understanding participants completed a six question pre-test which assessed the interviewee’s understanding of the Likert-type scale. (Appendix H) The pretest served two purposes: a) it was a strategy for ensuring that the

individual was able to reliably respond to the Likert-type scale and b) it provided a training opportunity for participants to distinguish among response alternatives. The pretest responds to the threat of response bias and poor internal consistency. 2) I included clarifying questions following a sparse participant response to the initial question. Clarifying questions, such as, “tell me more about it” or “do you want to add anything” ensured that the question was understood and that the answer reflected the person’s belief or intention. Such a strategy increased the validity and the internal consistency of the Likert-type scale. Additionally response bias was reduced through the use of clarification. 3) I paraphrased and/or expanded on the question or the response if the participant seemed unclear. The need for this extra help frequently occurred when the question contained negatives, such as, “I could say that what I do doesn’t have a good/positive effect on other people.” Considering the need for consistency in presenting the questions to all participants, a scripted rewording was used and included on the instrument itself, as recommended by Hartley and MacLean (2006, p. p.818). The strategies listed above and the feedback from the individuals on the specific instruments used in this research addressed issues related to understanding of the questions and Likert-type scaling.

Quantitative Measures

Interviewees completed three standardized instruments: the Loyola Generativity Scale (LGS); Generative Behavior Checklist (GBC), and the Satisfaction with Life Scale (SWLS). I administered the quantitative instruments following the life story interview, allowing time for the individual to become comfortable with the interview process. To avoid potential literacy problems I read the questions and transcribed the participant’s answers.

Loyola generativity scale (LGS). The Loyola Generativity Scales allows persons “to rate the extent to which they agree or disagree with 20 statements designed to assess the strength of a person’s overall conscious concern for the next generation” (McAdams, 2006b, p.308). McAdams and de St. Aubin (1992), who developed and validated the Loyola Generativity Scale, consider it one of the most psychometrically reliable and valid scales for this research area. The LGS taps three of the seven features included in the concept of generativity; generative concern, generative action and personal narration (McAdams, 2006a; McAdams & de St. Aubin, 1992; McAdams et al., 1998). Sample questions from the instrument include: “I try to pass along the knowledge that I have gained through my experience; I do not feel that other people need me; and I try to be creative in most things that I do.” In studies completed by McAdams and de St.

Aubin (1992) “LGS exhibited good internal consistency and retest reliability and showed strong positive associations with reports of actual generative acts and themes of generativity in narrative accounts of important autobiographical episodes” (p. 1003).

In a second study conducted by McAdams and de Aubin (1992) :

(A) test-retest on the LGS and examined how LGS scores for generative concern relate to indexes of generative behavior and generative narration as assessed in objective reports of real-life behavioral acts and in open-ended descriptions of personally meaningful autobiographical events... The focus on autobiographical events affords a second, albeit subjective, perspective on action and allows one to assess generative narration through the content analysis of personal experiences. (p. 1007)

The McAdams and de St. Aubin, Loyola Generativity Scale (LGS) is located in Appendix Ca, followed by the adapted version (Appendix Cb)

Generative behavior checklist (GBC). In McAdams and de St. Aubin’s original work, the Generative Behavior Checklist measured generativity through 65 items phrased as behavioral acts.⁴ The individuals checked those activities in which they were involved and how many times they had performed each in the past two months (McAdams & de St. Aubin, 1992). In their study for validity and reliability they found that

of the total, 49 acts were chosen to suggest generative behaviors, and 16 were chosen as acts that appeared to be irrelevant to generativity....By and large, each act corresponded to one of the three main behavioral manifestations of generativity: creating, maintaining, or offering. (p. 1010)

Samples statements from the Behavior Checklist included: “taught somebody a skill; listened to a person tell me his or her personal problems; and attended a community meeting”. After additional study, the checklist included 50 items, with 10 items considered as “filler” and unrelated to generativity. The scoring of the GBC eliminated these 10 items resulting in a maximum score of 80. (<http://www.sesp.northwestern.edu/foley/instruments/gbc/scoringgbc/>) A copy of the GBC is located in Appendix D.

⁴ Earlier versions of the Generative Behavior Checklist are identified as the Loyola Behavior Checklist (LBC), for consistency GBC is used except for direct quotes which include the LBC.

From their data analysis, McAdams and de St. Aubin (1992) defined the five generativity themes as creating, maintaining, offering, next generation and symbolic immortality.

Relationship between the Life Story Interview and LGS and GBC. McAdams and de St. Aubin (1992) explain the relationship between the life story interview and the LGS and the GBC: Two independent coders scored the autobiographical episodes for themes of generativity. Scores were summed across themes and episodes for each subject to arrive at a total generative theme score for each subject. Interrater reliability achieved a correlation of .88, suggesting high interrater reliability (McAdams & de St. Aubin, 1992, pp.1010-1011).

There is significant association between the Life Story Interview theme scores and the LGS $r(61) = .40, p < .01$; and the sum of 49 generative acts (GBC), $r(61) = .45, p < .001$; “suggesting substantial convergence among the three methodologically distinct assessments of generativity” (pp 1011-1112).

The second study found similar associations between the LGS scores, the generative acts on the GBC and the themes of generativity in autobiographical narration or Life Story Interview: “Thus, assessments of generativity from the standpoints of concern, action, and narration would appear to converge on the general construct of generativity from three different but related angles” (McAdams & de St. Aubin, 1992, p. 1112).

Satisfaction with life scale (SWLS). The Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985) addresses global or general life satisfaction. (See Appendix B for a copy of the SWLS.) It is a measurement of an overall evaluation of life, rather than specific domains or satisfaction with life as a whole. General life satisfaction is defined as “a global assessment of a person’s quality of life according to his chosen criteria” (Shin & Johnson, 1978, p.478, quoted in Diener et al., 1985, p.71). The SWLS serves as a companion instrument to the other three instruments as it allows for the interviewee’s subjective or internal comparison of his/her life satisfaction. Diener et al.’s instrument is a five item scale that asks interviewees to score each item 1-7, yielding a total range from 5 (low satisfaction) to 35 (high satisfaction). As discussed earlier, to address potential problems in answering a Likert scale, the 7 point Likert-type scale is modified to a 5 point scale, reducing the risks of lower internal consistency and higher response bias. Ranges for the adapted version are 1 (low satisfaction) to 25 (high satisfaction). Sample questions from the SWLS include: “in most ways my life is ideal and so far I have gotten the important things I want in life.”

Diener et al. (1985) found the SWLS to have favorable psychometric properties, including high internal consistency and high temporal reliability (p. 71)...Scores on the SWLS correlate moderately to highly with other measures of subjective well-being... It is noted that the SWLS is well suited for use with different age groups... (p. 71).

Diener et al. (1985) conducted three studies on the reliability and validity of the SWLS. Findings were that the two-month test/retest correlation coefficient was .82 and coefficient alpha was .87. The inter-item correlation matrix was factor analyzed, using principal axis factor analysis. The number of factors to be extracted was determined by an inspection of the scree plot of Eigen values. Using this criterion, a single factor emerged, accounting for 66% of the variance (Diener et al., 1985,p. 72).

Authors then examined the relationship between the SWLS and other subjective measures of well-being. Findings were “(I)t appears that individuals who are satisfied with their lives are in general well adjusted and free from psychopathology” (p.73).

Diener, et al., then completed a third study that included an interview, completion of the Life Satisfaction Index (Adams, 1969) and the SWLS. Interviewers also rated subjects in terms of Global Life Satisfaction on a 7 point scale. The inter-item correlations for five SWLS items were .81, .63, .61, .75, and .66 showing a good level of internal consistency for the scale.

De St. Aubin and McAdams (1995) used the Satisfaction with Life Scale to examine or confirm the relationship with generative concern and life satisfaction. Of note, while finding a relationship between generative concern and life satisfaction, they did not find a relationship between generative behavior and life satisfaction.

Summary. Taken as a group the Life Story Interview, the Loyola Generativity Scale and Generative Behavior Checklist address the generative motivational features of concern, action and narration, the behavior or actions supporting those motivations and offers a “thematic assessment of critical autobiographical experiences that taps into generative narration in one's self-defining life story” (McAdams & de St. Aubin, 1992, p.1006). The three instruments focus on three aspects of generativity: generative concern, generative goals, and generative measures (McAdams & de St. Aubin, 1992; McAdams et al., 1998). In an updated evaluation of the psychometric reliability and validity of the Life Story Interview, McAdams (2006b) states that “(m)asures of generative concern, generative goals, and generative acts tend to be positively correlated with each other. Of the three measures, the LGS has the most psychometric reliability

and validity...” (p. 308). The Satisfaction with Life Scale complements these specifics of these instruments and adds the broader concept of life satisfaction for comparison.

Collection of demographic data. Demographic data regarding age, gender, race, residential/living arrangements, county of residence, primary day activity, i.e. work, day activity program or other, current sources of income, family composition, and educational history were collected (Appendix I). Data analysis explored group comparisons as well as the understanding of the individual’s own life story.

Qualitative Measure

Life Story Interview. McAdams (1993) developed the interview format used in this study. He acknowledged that the format was fluid and changed as needed: “there is nothing sacred about any of these interview protocols. We routinely modify the procedure to fit the research question at hand, which is what I also encourage other researchers to do” (McAdams’ personal communication, 3/5/2010).

The interview process for this research followed McAdams’ interview sequence (2010a). However, there were modifications to McAdams’ Life Story Interview use of questions structured around a book format, beginning with the participant describing her life as if it were a book with chapters. Following consultation from individuals with intellectual disabilities regarding possible unfamiliarity with a book’s structure, I employed the metaphor of life as a movie with scenes, rather than a book with chapters. The following reflects the adapted version used for this research. 1) The interviewee was asked to think about her or his life as if it were a movie and to name the movie. The movie was then described by scenes. There was not a maximum of scenes. 2) The interviewee was asked to describe eight key times or events that were especially important or life changing. These episodes included high point, low point, turning point, earliest memory, important childhood episode, important adolescent episode, important adult episode, wisdom episode, spiritual episode and one other important episode. The interviewer encouraged the interviewee to add as many details as possible, including age, place, people involved, feelings and perceptions about the event and how the specific event fits into to the overall life story. 3) The interviewee was asked to talk about her biggest life challenge, how it developed and how she met this challenge. 4) The interviewee was asked to identify and describe two persons (or institutions), one the most positively influential and the other the most negatively influential in her life. 5) The interviewee was asked to name a new movie sequel,

depicting one's future, including dreams, goals and fears. 6) The interviewee was asked about personal values and beliefs and how these have developed over time. 7) The interviewer asked the interviewee to look back over her entire life and to talk about a major life theme(s) that seemed to run throughout the story (movie). 8) Lastly, the interviewer asked the interviewee if there was anything else that she would like to add to the discussion.

Study Sample

Sample Selection

This research used a stratified purposeful sampling method of twelve persons with mild intellectual disabilities, ages 21-65 years, soliciting interviewees through local agencies serving persons with intellectual disabilities. Staff provided the referrals, based on the researcher's guidelines, for likely placement of the interviewee in either the higher generativity group or the lower generativity group. When selecting the sample, I included males and females, African Americans, Caucasians and adults from a range of ages; however, I did not specifically stratify the sample by sex, age, class or race as the focus of this was not to compare the experiences of persons in different demographic categories; rather it was to explore the experiences of adults with intellectual disabilities who are and are not highly generative individuals in their community and to understand each person's sense of identity making, with reference to agency, communion, redemption, contamination, stagnation and generativity.

Purposive sampling is appropriate when the expertise of the participant is important in providing relevant information, rather than being representative of a wider population (Bogdan & Biklen, 1982; Miles & Huberman, 1994). Stratified purposive sampling is appropriate when the subgroups will facilitate comparisons (Miles & Huberman, 1994, p. 28). In personal email communication with McAdams (2010b), he suggests that

comparing 6 high-gens to 6 low-gens, gives you the advantage of being able to distinguish themes that show up in one group but not the other. I think the second (option) is somewhat preferable, in that with the first (option of interviewing 12 high-gens) you can't really say that what you found wouldn't also show up in a 'contrasting sample.'

This sample number of 12 allowed for a range of adults and ensured a sufficient number of interviews to achieve theoretical saturation, that point at which emerging themes reach their saturation point and new themes are no longer present (Guest, Bunce, & Johnson, 2006). Sample size of 9-15 is frequently seen in the literature for qualitative methods (Glazer & Strauss, 1967;

Guest et al., 2006; Miles & Huberman, 1994). Guest, et al., in their research on how many qualitative interviews are enough, demonstrated that if the goal is to describe a shared perception, belief or behavior among a relatively homogenous group, a sample of 12 is sufficient. In the field of disability research, Marshall (2007) using purposive sampling to explore the identity formation of young women with Turners Syndrome also used a sample of 12.

Inclusion/Exclusion Criteria for Participants

Inclusion criteria for participants were: a.) between the ages of 21-65 years, b.) able to engage in a question and answer and discussion format, c.) possessed episodic memory, d.) possessed capacity for self-definition, e.) attended special education classes at some time during school years, f.) aware of being labeled as “slow, slow learner, mentally retarded, or intellectual disabled” and g.) received services from the county board of developmental disabilities. Exclusion criteria were: a) not own guardian, b) unable to maintain attention to a conversation for less than thirty minutes.

Rationale for criteria. Whitney-Thomas and Moloney (2001) propose the idea of self-definition as knowing what one wants in life and having a mechanism to achieve goals. This mechanism includes problem-solving, choice and decision making skills, self-awareness, clarity of personal vision and adaptability. Cognitive processes of self-definition include future orientation, identity formation, cognitive skills that support decision-making and introspection. Also included is McAdams’ (2006) criterion that the individual possesses episodic memory, i.e. the ability to recall specific events from the past. I informed those persons assisting with recruitment of the criteria (see recruitment and consent section). The inclusion criteria of mild intellectual disabilities were vetted by the county board of developmental disabilities, which requires documentation of disability for service provision.

Participant Recruitment

The recruitment process initially involved a series of meetings with advocates with disabilities, county board of developmental disabilities staff and staff from other disability agencies. I located my interviewees through the efforts and thoughtful consideration of staff that became aware of my scholarly interest in this population. Staff made the initial contact with the potential interviewees asking if they would be interested in talking with someone about their life story. Additionally the staff told them that I was a social work student who was conducting the

interviews for research purposes. They were told that this was voluntary and that agreeing or not agreeing would not affect the service that they were receiving from the agency. If they expressed an interest, the staff asked for permission to give me their contact information. Only one potential interviewee turned down the invite to participate. The other twelve individuals expressed an interest in telling their stories as well as an understanding of the potential significance of positively impacting the lives of others with intellectual disabilities. In this sense, they all shared in the generative nature of this research. This researcher conducted all twelve interviews.

At the first meeting, I read the “Consent to Participate in a Research Study” form (Appendix J) and encouraged questions about the content. In addition to my informal assessment during the normal consent process regarding understanding, participants completed a formal post-consent quiz, *Brief Assessment of Capacity to Consent* (Appendix K). This consent form, based on the University of California, San Diego Brief Assessment of Capacity to Consent and approved by the IRB, addressed the recommendation of Subcommittee on Inclusion of Individual’s with Impaired Decision-Making in Research (SIIDR) of the Department of Human Services Secretary’s Advisory Committee on Human Research Protections and now considered best practice (Jicha & Walker, 2009; University of California San Diego, 2010) This additional step addressed the elements of understanding, reasoning and appreciation (Jeste et al., 2007).

After successful completion of the Brief Assessment quiz, the individual signed and dated the consent to participate form. Copies of the signed consents were given to those participants who desired one.

Also at the initial meeting participants choose a \$10 gift certificate from a list of stores and restaurants. This gift certificate was later given to them. The first meeting also initiated data collection which is described in a later section.

Protection of research subjects. Interviewees’ confidentiality and anonymity was assured in the following ways: a.) keeping study records in locked files, b.) storing information on a password protected computer, c.) disconnecting all identifying information from transcripts which were read by second readers, d.) using a confidential transcriptionist for audio transcription, e.) assignment of pseudonyms to interviewees for reporting of data.

Institutional Review Board procedures. This research was approved by the University of Kentucky Non-medical Institutional Review Board. Letters of support to conduct research at

Hamilton County Developmental Disabilities Services and Starfire were submitted to the University of Kentucky Institutional Review Board.

Data Collection

Twelve individuals participated in face-to-face semi-structured interviews, using an adapted version of the Life Story Interview (McAdams, 2010a) and completed the Generative Behavior Checklist, Loyola Generativity Scale (McAdams & de St. Aubin, 1992), Satisfaction with Life Scale (Diener et al., 1985) and the Demographic Data sheet. Study data were collected between April 2011 and August 2011. The Life Story Interview was digitally taped. Other data collected included: general field notes about the interviewee and the interview setting and collateral contacts. I did not solicit collateral contacts, however, a few interviewees urged me to contact their DDS case manager for some details that they could not provide. Table 3.1 found at the end of this chapter visually describes the connection of the data and data collection method to the research questions and to research topics discussed in chapter 4.

The in-depth and multiple interviews were conducted in nineteen sessions, with seven participants meeting twice with the researcher. Each session ranged from 45 minutes to 2 hours in length. The digitally taped life story interviews ranged from approximately 30 minutes to 2 hours. A total of 18 hours 46 minutes of taped interviews were collected and analyzed. At minimum the following occurred during the first meeting: completing the written informed consent, completing the demographic information and beginning the life story interview. During the second interview, if necessary, the life story interview was completed as well as the quantitative measures.

Research with persons with intellectual disabilities supports relationship building in order to establish trust and communication. This relationship- building occurred immediately at the time of the first interview. Several researchers (Goodley, 1998; Knox & Hickson, 2001) recommend a check in the interviewing process of interviewing, allowing the interviewer to review responses with participants in order to reflect accuracy and to ensure what Bloor (1978) called respondent validation. For this research, positive attention and checks to the accuracy of interviewer's understanding occurred frequently. Second interviews occurred with 7 participants, and reaffirmed or allowed for adjustments in the interviewees' answers to earlier questions.

All the individuals participated with enthusiasm and shared their personal stories. Most used concrete realistic titles for their life movies when asked to title their life, such as *Carl*

Duggin's Life. Others used significant events, such as Greg's title, *Living on the Railroad*. The interviews were not only rich in meaningful individual history but also local and national historical contexts, such as the impact of events of September 11, 2001, or being chosen as a batboy for a major league baseball team. For some, an initial hesitancy transitioned into a sincerity of narrative recall of events most significant to whom they are today.

The occasional challenges that presented themselves during the interview process were related to understanding specific words or concepts, such as "wisdom" or "values." For the interviewer the challenge was in understanding the actual articulation of the interviewee as well as sequences of events.

Additionally, three males—Carl, Ed and Greg--interwove stories of fantasy with stories of actual events. During these times I employed a variety of strategies either at the interview stage or data analysis stage. For example, I directly asked Carl, "Did this really happen, or do you want it to happen?" (e.g. become head coach of a local girls' basketball team). Carl would then clarify his statement. Another strategy was to ask later in the interview for a recap of the scene and to then ask for clarification of what actually happened or what was "wished" to happen. During data analysis these scenes were set aside and not included. Despite these wishful story lines, the three interviewees provided a wealth of usable data.

Data Analysis

Using a mixed methods approach, the first consideration of data analysis involves data reduction. The data for this research originated from the twelve life story interviews and the completion of the three instruments, LGS, GBC and SWLS. Collateral data from referral sources was used sparingly and to confirm details, not to add to the content analysis. Such information provided substantiation for convergent validity or confirmability specifically regarding questionable details provided by the interviewee.

Analysis employed McAdams' coding schedules for the identified key concepts of agency, communion, redemption and contamination of this research. The coding schedules are included in Appendices E, F and G.

In addition to the coding schedules, content theme analysis allowed the research to generate others factors and concepts which informed the identity making process of the interviewees. Beyond use of the coding schedules and thematic content analysis, this research explored patterns of relationships between the findings from the various instruments, including

the qualitative interviews and the quantitative measures (LGS, GBC, and SWLS). (Table 3.2 describes the analytic method for answering the research questions.)

Qualitative Data Analysis

Guidelines for qualitative data analysis. This research followed Miles and Huberman (1994) and Fraser's (2004) guidelines for qualitative data analysis. Fraser describes this iterative process in five phases, including 1) experiencing the interview, 2) transcribing or recording the interview, 3) interpreting or identifying and analyzing content, 4) discovering commonalities and differences within the individual stories and 5) writing the findings (Fraser, 2004).

During Phase 1, I recorded my impressions and significant details not captured on tape, by the quantitative tools through the use of a contact sheet. (Appendix L). These were for my notes and for use if it added to the analysis. For example, Otto, post-interview, suggested a name of an African-American woman as a potential interviewee. He offered this name, understanding the need for diversity within the sample. Following another post-taping, Greg offered that he had two children. I also typed initial notes of impressions and details to remember post-interview. The immediacy of this activity increased data analysis reliability.

During Phase 2, independent transcribers transcribed the digital taped interviews, including the pauses and verbal gestures (ex. laughing). Inclusion of these gestures and pauses increased the data analysis reliability. Transcription of the data occurred simultaneously with the interviewing process, allowing for changes/additions to the interviewing process to enrich the data collection. Prior to sending the tapes, I listened to the interview and if, necessary, provided a list of words and phrases which posed potential problems for the unfamiliar transcriber. Upon receipt of the transcript, I again listened to the tape, this time, comparing the typed transcript to the taped audio. Changes were made as needed due to mistakes related to the transcriber's difficulty in understanding pronunciations, names of specific places or names and/or interviewees' accents.

In qualitative research, the data analysis often drives the ongoing data collection. Also, during this phase I received feedback from the interviewee, checking for accuracy of what was said and accuracy for understanding. If necessary, follow up questions were added for a fuller picture of the individual's life story.

Qualitative theme exploration. Occurring simultaneously with the above process was phase 3, the coding process. This simultaneous activity follows Miles and Huberman's (1994)

suggestion: “(a)lways code the previous set of field notes before the next trip to the site” (p. 65). From the time of the initial review of the taped interviews observation notes were taken and then later incorporated and further developed using the transcribed interview. The transcribed interview was read a minimum of two times, with more frequent reading of specific questions. Observation notes included direct reference or connection to McAdams’ key concepts and other exploratory comments, more so related to research questions 8 and 9. Coding of the interviews was not consistently completed at the end of each interview, due to transcription issues.

The coding of the qualitative data consisted of two major tasks: a) analysis of the life story interviews using the McAdams scoring guide and b) data analysis of the life story interviews for content to identify other significant thematic areas, major and minor, and specific analytic domains. Miles and Huberman’s (1994) methodological framework provided direction in the use of an inductive open coding method. From each interview notes developed which consisted of reoccurring themes found in the interview. The themes found in the individual interviews were compared with others. From this iterative process, inclusion of, clustering of, collapsing of, and enlarging of conceptual categories developed. (Miles & Huberman, 1994; A. L. Strauss & Corbin, 1994) These categories were used to compare between the lower and higher generativity groups and within each group.

McAdams’ scoring guides. Transcripts of the 12 Life Story interviews were analyzed using McAdams’ Coding System for Themes of Agency and Communion, Redemption Sequences, and Contamination Sequences. (See appendices E, F, G) The Life Story Interview (see appendix A) is completed using a series of questions in which interviewees are asked to describe key times or events that were especially important or life changing. For this research, 148 key events or scenes were analyzed using the coding schedule. These scenes included the high point, low point, turning point, earliest memory, important childhood episode, important adolescent episode, important adult episode, wisdom episode, spiritual episode, one other important episode and future scene. For coding purposes the unit of analysis was the memory or scene.

All interviews were coded by the primary researcher. To address inter-rater reliability, two blind coders, both doctoral social work students, were used; one coder for the themes of agency and communion and one coder for redemption and contamination scoring. Neither coder

had any other involvement with the study. Information was shared regarding the focus of the study as well as background literature regarding the coding rationale.

Agency and communion. Inter-reliability agreement was .95 for agency codes and .98 for communion codes. A total of 105 different scenes were compared between the primary researcher and second rater. This agreement was considerably higher than the proposed .85 inter-reliability. The researcher provided the second rater with interview sections that related to the significant life scenes from seven interviews. The researcher picked the interviews randomly. The initial codings, done by primary researcher, and those of the blind coder were compared for matches. The blind rater completed her first coding pass and returned the codings, with comments, to the primary researcher who again compared for matches. The majority of first run codings achieved the accepted .85 agreement, however, a second reading was conducted in order to reach higher coding consensus. In these cases, the coding and transcriptions were returned to the blind rater with the primary researcher's comments. This process continued until agreement was met or considered acceptable by the primary researcher.

After completion of the matching of the seven transcripts by both the second rater and the primary researcher, the primary researcher reviewed the original scoring of the remaining five (non-second rater interviews) interviews. This second review was done due to the finding that the initial scoring of the reviewed seven transcripts was more liberal with points scored than that of the second rater. In an attempt to rebalance the scoring and avoid an inflated scoring on the five transcripts, the primary researcher reviewed and readjusted the scores on a few of the transcripts. For example, the first interview (Vicki) scored by the primary researcher scored higher than the subsequent review. Upon reading the second time, a more literal reading of the narrative occurred than previously, resulting in a lower score.

Redemption and contamination. The second blind coder received selected significant life scenes from 6 interviews randomly chosen. The coder received similar instructions as described for the first coder. The process of comparison between the primary researcher and second coder was also similar to that of the process of the first coder. The inter-rater reliability was 100% with sixty scenes different scenes compared.

Quantitative Data Analysis

Scores from the Loyola Generativity Scale, Generative Behavior Checklist and Satisfaction with Life Scale were computed. Averages were calculated for the total sample, each

group, and by various demographic data such as, age and gender, and comparison made within and between groups.

Levels of analysis. Once quantitative and qualitative data were coded and scored, analysis proceeded on three levels: 1) individual level, 2) within group level and 3) between group level. Each level provided a basis of comparison and further exploration of similarities and differences between the subsamples.

Individual assignment to Higher and Lower Generativity Groups.Phase 4 of data analysis also involves the exploration of meaning within each group and between groups. For this research the two groups, lower and higher generativity, were created for exploration and comparison purposes.

Group assignment occurred following data collection and initial data analysis of the quantitative measures. The group selection criteria was compatible with those factors measured in the Loyola Generativity Scale and Generative Behavior Checklist (McAdams & de St. Aubin, 1998;McAdams et al., 1998). These quantitative measures were developed from the definition of generativity, which includes the components of generative concern, generative goals, and generative measures. Table 3.3 Group Selection Criteria, found at the end of this chapter, details these criteria.

The process of assignment was as follows: total sample average scores for the Loyola Generativity Scale and Generative Behavior Checklist were obtained by averaging the scores of all 12 interviewees scores. Individuals were assigned to group 1, Higher Generativity, if they scored average (42.5) or higher on the Loyola Generativity Scale (LGS) and average (29.25) or higher on the Generative Behavior Checklist. Tables 3.4 and 3.5 list individuals and their group assignment.

Using this assignment method, Group 1 included 7 individuals and Group 2, included 5 individuals. One Group 1 individual, Vicki, did not meet the criteria of the LGS, however, she did meet the criteria of GBC with a score of 40. The simplest and most effective placement decision was to include Vicki in Group 1 as she best fit this group. Group 2 members' actual LGS scores were 36 points or less. Group 1 members' scores (excluding Vicki) were 47 points and above. Group 1 members' actual GBC scores were 31 points and higher (Vicki squarely fitting in this group with 40 points) and Group 2 members' scores for the GBC were 21 points

and less. Vicki's story did not show any exceptional differences from others in Group 1 to warrant a stand-alone outlier category.

Analytic decision-making process for use of data to address research questions and research topics. The twelve individuals provided richly detailed stories, allowing for exploration of meaningful experiences that impacted the formation of their identity. Considered analysis to explore this process included the use of specific scenes. These scenes included the turning point, high point, low point, important childhood memories, wisdom, religious, and future. The McAdams' coding systems for themes of redemption and contamination and agency and communion provided one framework for analysis.

In addition to analyzing the scenes, responses to the following Life Story interview questions were explored. 1) How do you imagine your future (or future plot of your movie)? 2) What are the themes that go through your life (or movie of your life)? 3) What does the movie say about you or what do you want people to know about you? 4) Tell me about your values and beliefs. 5) How do you think you have lived those beliefs and values? 6) Have your values and beliefs changed over time and if so, how?

Each question offered the interviewee opportunity to reveal his or her generative intent, by imagining their future, and thus revealing their values and intent or speaking directly about their values or beliefs. In their answers regarding what the movie says about them or what they want people to know about them, the interviewees exposed their hoped-for perception of how others saw them thus also revealing how they witnessed themselves. Motivation and actions are revealed through these answers.

Additionally, employing a stepwise approach, individual stories were first analyzed for individual life story themes. Examples from these stories then illustrate the broader aggregate findings of the stories.

The analytic process of qualitative research allows for discovery of themes, patterns and exceptions to those. A stepwise approach from individual to the aggregate findings occurred in order to answer to the research questions and to explore the research topics. Through the use of data notes written during the data analysis phase and reporting findings phase in addition to several readings of the transcripts an iterative process occurs. This process yields a "thick description" of individuals' life stories. Included in this stepwise approach is the agreement process method (Neuman, 2000, p. 421). From this method, the reporting of findings includes

not only the individual story but also the collective story of twelve individuals. The method of agreement process yielded commonalities across the life stories and initiated themes for further exploration and refinement.

Scene Descriptions

Turning point scene. “Turning points are narrated events with long-lasting consequences” (Schultz, 2001, p. 73). The individual self-evaluates those events considered as defining moments of changing the “individual’s previous trajectory” (Schultz, p. 73). This change may involve a shift in meaning, purpose or direction of a life (Wethington, Cooper, & Holmes, 1997, p. 217 as cited in Shultz, 2001, p. 73).

High point scene. The high point is explained to the interviewee as the “greatest thing that ever happened to you, or the happiest time of your life” allowing for the individual to focus initially on either an event or a feeling of happiness.

Low point scene. Conversely, the individual is asked to describe or talk about the saddest time or the worst thing that ever happened.

Earliest childhood and additional significant childhood scenes. These scenes bear witness to the individuals’ meaningful experiences during the key early developmental years and the development of one’s striving for unity and purpose in life. This unity and purpose shows itself with the concepts of agency and communion. Adler (1992) among others (McAdams, 2009) considered one’s earliest memories as revealing major themes in a person’s style or life and setting the stage for how one adjusted to life. Adler regarded the earliest memories as the beginning of the self-creation myth, or the “overall tone of the person’s subsequent life story” (cited in McAdams, 2009, p. 459). When analyzing an individual’s early memories, the researcher seeks to understand feelings and actions of control and power (agency) over one’s life. The patterns and themes that emerge regarding one’s connection to others (communion) share equal importance in the understanding of an individual’s sense of self. The family, with its parental-child and sibling relational patterns, prevails as a dominant influence during this early developmental period.

Future scene. The future scene explores the interviewee’s anticipated future and what it holds regarding agency and communion themes and generative action. Based on the subjective early experiences, individuals create a “hoped for future” (McAdams & Bowman, 2001). Exploration of the future scenes provides an analysis of the connection or disconnection between

the subjective memory and the personal vision for the future. We remember our past based on our imagined goals and personal strivings (McAdams, 2009). The future scenes reveal what we want to or expect to become.

Wisdom scene. In the wisdom scene the interviewee is asked to share a time in which wisdom is shown either in advice that the interviewee gave to someone or in a personal decision or choice. The interviewer asks the interviewee to explain what this decision or advice says about the interviewee. Exploration of the scene provides an analysis of the interviewee's self-insight as well as sense of personal agency. The interviewee's moral development also may reveal itself in this scene.

Religious or spiritual scene. As McAdams' explains in the life story interview format, many people report that they have had experiences in their lives where they felt a sense of the transcendent or sacred, a sense of God or some almighty or ultimate force, or a feeling of oneness with nature, the world, or the universe.

The interviewer asks the interviewee to share a time when she felt God's presences or something or someone larger than herself in being present in or guiding her actions. The exploration of this scene provides data regarding one's sense of religiosity and belief system, such as, extrinsic or intrinsic orientation. Similar to the wisdom scene, analysis may reveal data regarding one's moral or faith development.

Definition of Concepts

The concepts of communion and agency, redemption and contamination are central tenets of personal identity development as considered in this research.

Communion. Communion, for purposes of this research, refers to "joining the self with others in bonds of love, friendship and community" (McAdams, 2006b, p.244). By its definition communion is interactional, addressing one's relationship to others.

Agency. "Agency refers to the tendency to expand, defend, or express the self" (McAdams, 2006b, p. 244). Agency answers the question: How much control do I have over my life? Using the same decision-making process to answer the previous questions, agency and communion themes were analyzed for each interviewee.

Redemption. Redemption scenes occur when "the initial bad state or event leads to a good state or event, but the good does not typically undo or erase the bad." (Appendix F, Coding for Redemptive Sequences) The redemption story may score additional points for highlighting

enhanced agency, enhanced communion and ultimate concern. Enhanced agency indicates an added sense of agency or personal power, more than the expected agency in a redemptive scene. Enhanced communion indicates an added sense of personal relationships. Ultimate concern addresses the fundamental existential issues of life and indicates a strong spiritual dimension or powerful personal meaning to the individual. (See Appendix F, Coding for Redemptive Sequences).

Contamination. In a contamination scene, what began as good or positive ends as negative or bad, became bad or negative. The positive feelings of pleasure yield to negative feelings, such as fear, shame, guilt or sadness. The essential component to a contamination scene is that, “(T)hings get worse”. (See Appendix G Coding for Contamination Sequences).

Developmental process. The developmental process considered here refers to the typical progression of psychosocial growth or maturity characterized by an individual’s incorporation of agency and communion into one’s identity or sense of who they are, how they behave, and what motivates their actions.

Generativity. “Generativity is an adult’s concern for and commitment to promoting the well-being of future generations” (McAdams, 2006b, p.4) . Instruments employed in this research capture the generativity and stagnation themes of the interviewees’ life stories. The Loyola Generativity Scale and the Generativity Behavior Checklist quantify the generativity intent or motivation and behavior. The Life Story Interview offers narrative exploration of these generative themes. Qualitative analysis of the Life Story Interview also yields data pertaining to the interviewees’ generative concern or motivation and resultant actions (McAdams, Hart, & Maruna, 1998; McAdams & de St. Aubin, 1992).. Behaviors regarded as generative relate to the values of social commitment, altruism, life-long learning and the development of self-understanding. (<http://www.sesp.northwestern.edu/foley/>).

Stagnation. By definition, stagnation suggests lack of movement or involvement. A stagnant person is “unable to generate outcomes that extend their care and commitment to future generations” (McAdams, 2006b, p. 220) A stagnant person finds “it very difficult to ascribe overall direction and purpose to their lives” (p. 217).

Level of Analysis

For presentation and explanatory purposes, the overall demographic picture is presented. Levels of analysis occurs as follows: 1) within case analysis or the individual level; 2) within group or the intragroup level and 3) between group analysis or intergroup analysis.

Total sample analysis. It is important first to understand the sample as a whole. Included in this analysis were demographics, analysis of quantitative scores (LGS, GBS, SWLS) and Life Story coding scores.

Within Case Analysis

To fully understand within cases and subsequently cross cases the researcher must understand the context within which the individual's story takes place. This exploration guides the development of propositions into broader exploration of meaning within and cross cases (Mishler, 1986b). Two methods of data examination were used; exploration through the use of quantitative scores for the key concepts (agency, communion, redemption and contamination) and comparison to the total sample and through the use of portraits.

The within group analysis continues Fraser's (2004) Phase 4 of discovering commonalities and differences; this time comparing each interviewee's data within the same group. Within group analysis included comparison of several combinations of scores between the members of each respective group. Numerical scores of the LGS, GBC and SWLS were compared with the findings on agency, communion and redemption. Demographic characteristics, such as gender, religious activity, race, economic status and age were discussed in relationship to agency, communion, redemption and contamination.

Portraits

In its simplest sense, use of a portrait is a presentation technique of "the graphic portrayal in words"(Merriam & Webster, 1965). Qualitative research expands the use of a portrait, calling it a "pen portrait" as a method of creating and integrating "the elements surrounding the research encounter into a whole and to bring processes into one frame, enabling themes to emerge through gestalt moments of perception and understanding" (Merrill & West, 2009; West, 2001 as cited in Howatson-Jones, 2001, p. 41). Holley and Colyar (2012) described portraiture as "central method of documentation, analysis and narrative development (p. 114).

The pen portrait offers a template for recording the elements of an encounter, such as the history and context of the interview followed by the researcher's insights developed from the reflections

on the transcription. From this process themes emerge which connect the narrative and provide relevance to the analysis (Howatson-Jones, 2001, p. 41)

In the use of portraits as a methodological tool, one considers the question of validity from the perspective of authenticity, of how the research explains the particular in relation to the general; in terms of what the particular case says “about the structure and cultures in which they are embedded” (Howatson-Jones, 2001, p. 42). This methodology prioritizes the importance of not only the individual marginalized voice but the collective lives which “enables us to see the human condition in many new ways” (Howatson-Jones, 2001, p. 42). Pen portraits add contextual depth to an otherwise detached data collection method (p.38).

Between Group Analysis

At this level of data analysis, the life stories of each group are analyzed collectively and then compared between groups. Answering the research questions involved analysis of demographic indicators, quantitative scores for agency, communion and redemption, agreement process method for the life story interviews, and scores from the LGS, GBC and SWLS instruments.

The analytic method for exploring the research questions is similar to the methods discussed earlier. Comparison between Group 1 and Group 2 uses the specific scenes (turning point, low point, high point, future, religious/spiritual, wisdom and earlier childhood scenes) analyzed earlier with reference to the individual portraits and total sample. These scenes illuminate the identity making process with reference to the concepts of agency, communion and redemption. The concept of contamination is not explored due to the low number of such stories. This finding is meaningful in itself for the reason that it signifies the absence of a contaminated voice of the sample. A summary of the research process is displayed in Table 3.6.

Management of Threats to Reliability and Validity

Management of threats to reliability and validity were addressed in a variety of ways and can be categorized as safeguards prior to the individual interview, safeguards during the interview process and safeguards during data analysis. These safeguards addressed the issues of creditability, dependability and confirmation necessary for scientific rigor (Lincoln & Guba, 1985). (See Table 3.7 for extensive description of strategies for managing threats to validity and reliability.)

Prior to the individual interview the use of the focus group of persons with disabilities ensured adaptability of the instruments for cognitively developmentally appropriate wording. I adapted the instruments and the recruitment talk for literacy and cognitive challenges through the use of Flesch-Kincaid Reading Scale (Ogloff & Otto, 1991) (see Appendix M for recruitment talk). Typical attrition problems related to lack of transportation or scheduling were avoided by meeting individuals at their convenience in a setting of their choosing. The voluntary nature of the interview process, the encouragement of the referring agency staff to the individuals to share their stories and the small remuneration for individual's participation also contributed to an excellent participation rate. The use of standardized materials, audio-taping the interviews and one interviewer (this researcher) ensured consistency and control for personal interpretation.

Safeguards during the interview included the use of open-ended questions which encouraged individuals to describe themselves and their memories in their own fashion. (Corbett, 1998; Cunningham & Glenn, 2004; Flynn, 1986). Sources of error originate in many forms and in different stages of the research process. (See Table 3.7 at the end of this chapter.) Several challenges and issues face the researcher who interviews persons with intellectual disabilities. (Antaki, 2002; Antaki, Young, & Finlay, 2002; Biklen & Moseley, 1993; Booth & Booth, 1996; Goodley, 1984, 2000; Hartley & MacLean, 2006; Houtkoop-Steenstra & Antaki, 1997; Stalker, 1998; Walmsely, 2003) Goodley's (1984, 2000) work highlights a number of problems associated with "giving voice" when assumptions of "the disempowered" and "the special" are used in preconceiving the actions of research participants. These problems arise regarding 1) issues of methodology 2) writing of others' stories and 3) the research relationship.

Any research approach requires consideration of power differentials between the researcher and the "subject." This is especially true for research involving persons with intellectual disabilities.

In the interview stage, the interviewer must be aware of the possibility of shaping the participant's answer (Antaki et al., 2002). In their study of interviewers' styles with persons with intellectual disabilities Houtkoop-Steenstra and Antaki (1997) examine how the interviewer's reformulation and delivery of (ostensibly standard and neutral) questions preempt or minimize troubles in the interviewees' responses or encourages positive and optimistic responses. Regarding the use of yes/no questions, Antaki et al. (2002) noted that such questions are

easy to agree with, and hard to challenge, whether one has a learning difficulty or not. They tend very strongly toward confirmation by the respondent simply as a matter of the way the conversation is organized. (p. 448)

Others (Atkinson, 1988; Clough & Barton, 1998; Corbett, 1998; Finlay, 2002; Flynn, 1986; Heal & Sigelman, 1995; McVilley, 1995; Rapley, 1995, 2004; Rapley & Antaki, 1996; Sigelman, Budd, Spanhel, & Schoenrock, 1981; Wyngaarden, 1981) provide research into the problems of acquiescence and other response biases, such as choosing the last option offered or problems of recency potentially damaging the quality of the interview. Rodgers (1999) found challenges when asking persons with intellectual disabilities questions about how much or how often.

Rapley (2004) takes issue with the work of Sigelman et al. (1981) and Heal and Sigelman (1995) regarding the dangers of acquiescence in interviewing persons with intellectual disabilities. After analyzing several extracts of the interviews and questions posed by Sigelman and others, Rapley (2004) provides an alternative explanation to acquiescence:

Interviewees, if they are competent conversationalists, will, in the face of the demands set up by the utterances of the interviewer, change their position (and thereby seem to be ‘acquiescing’ in the motivated sense) until such time as the trouble brought about by these factors has been either averted or resolved. (p. 94)

Additionally, Rapley (2004) finds problems in the testing/interviewing situation and the context of the interviews conducted by Sigelman et al. Rather than distrusting the behavior of the interviewee, he considers the problem one of power differential. He cogently states, “(A)cquiescence is perhaps best understood as an entirely local response to what often amounts to blunt coercion, and hence reflects a highly acute judgment of the way things stand with ‘being intellectually disabled’” (p. 200). Questions of inconsistency and coherency may not be a “matter of a general, unaccustomed submissiveness, but rather a demonstration of attention to the matter and sequence of the way the test questions are put, and the large amount of surrounding material in which they are embedded” (Rapley, 2004, p. 110). The most recent work by Hartley and MacLean (2006) reinforces much of the previous discussion specifically regarding persons with intellectual disabilities answering Likert-type questions.

Individuals choose their time and interview setting, providing them a sense of control frequently missing in the lives of persons with intellectual disabilities. In the early stage of the

interview session the use of the *Understanding the Likert-type scale* and *Brief Assessment of Capacity to Consent* tool provided opportunities for assessment of cognitive abilities and possible ways of adapting the interview format for more dependable or reliable data collection.

Questions were asked in multiple ways with wording that was appropriate to the individual's cognitive ability. Following the interview, collateral data from the referral provided substantiation for convergent validity or confirmability specifically regarding questionable details provided by the interviewee.

Post-interview and during the data analysis phase the use of notes written immediately after the interview, including observations and conversations with referring staff, multiple readings of the interviews and listening to the digital tapes and use of second raters further addressed issues of reliability/dependability.

Researcher expertise. In qualitative research, the interviewer becomes an instrument for acquiring data. The subjective nature of human interaction poses an opportunity and a threat to the gathering of information and data analysis (Bogdan & Biklen, 1982; Ely, Anzul, Friedman, Garner, & Steinmetz, 1991; Josselson & Lieblich, 2003, 1993; Lincoln & Guba, 1985). As noted in an earlier section Lincoln and Guba (1985) provide criteria for qualitative methodology. One aspect of meeting this criterion is the researcher's expertise and pre-study ethnographic experience.

I initiated this study due to my thirty years of direct practice and administrative experience as a state certified Licensed Independent Social Worker working with persons with disabilities and my persistent academic interest in understanding the lives of persons with intellectual disabilities through a non-disability perspective. I value the understanding of each person's unique story and am cognizant of the societal silence imposed on the persons with intellectual disabilities. My clinical experience prepared me for the vigilance which must occur during the interviewing "of the need to overcome distance rather than creating it, moving what was Other...into a relation with us" (Josselson & Lieblich, 1993, p. 30). I also gained credibility with the interviewees in terms of my familiarity with the local culture including significant political and historical events related to persons with disabilities.

While recognizing the strengths inherent in experience, I acknowledge potential for researcher bias (Ely et al., 1991, p. 15). I addressed this issue in at least three ways, the use of an interview guide to provide consistency between interviewees, the use of a second reader for data

analysis and multiple listenings and readings of the transcripts to provide confirmability. Importantly, I remained aware of self-reflective of my biases, oftentimes coming face to face with them during data analysis. (Giorgi, 1985 as cited in Ely et al.,1991)

Demographic Characteristics of Sample

The sample was evenly distributed between men and women. Two of the 12 interviewees were African- American (1 male, 1 female). The average age of interviewee was 47.17 years, with a median age of 44 years and ages ranged from 26 to 65 years. Men in the sample had a higher mean age, 50.8 years, and median age, 52.5 years, than the women (mean age 40.5 years and median age 43.5 years). All interviewees were single at the time of the interviews. Two interviewees had children. One woman had a young son who lived with his maternal grandmother and one man had adult children and young grandchildren.

Regarding religious affiliation, five of the twelve considered themselves Catholic, with four of the five describing themselves as active members. Other represented religions/denominations included Jewish, Christian Fundamental, Presbyterian, and Quaker.

Three of the twelve labeled themselves as having Down syndrome, with the remaining either not declaring a known cause for their disability or citing some type of brain trauma in their early childhood years. One-half of the interviewees worked at least part-time in paid positions. One woman was enrolled in on-line college classes, one young man participated in an adult transitional program which included community volunteer work, an older woman (age 56) neither worked nor volunteered and one man spent his days volunteering with persons who were homeless. Those interviewees who were in paid work also volunteered in other areas, such as, senior services or disability advocacy work.

Interviewees lived in a variety of residential arrangements including living alone (6), living with housemates (3) and living with family members (3). Four of the twelve received some type of residential supervision, ranging from the minimal of an emergency call button to in-home staffing. A summary of the demographic characteristics are displayed in Tables 3.8 and 3.9.

Comparison of Sample's Demographics to US Population of Persons with Mild Intellectual Disabilities

The demographics of the total sample in many ways reflected the demographics of the population of individuals with mild intellectual disabilities. Similar to this sample, Snell

et.al.(2009) observed that “(T)here is considerable variation in the lifestyle outcomes achieved by adults with intellectual disability who have higher IQs” (p.219).This sample appeared similar to the population of persons with mild intellectual disability in the areas of housing and income; i.e., 50% lived alone and the majority fell below the poverty threshold (Stancliffe & Lakin, 2007).

The interviewees were similar to the US population of persons with mild intellectual disabilities in experiencing a high level of unemployment. Those in the sample who did work were employed in part-time and in service jobs, similar to the larger population of persons with mild intellectual disabilities (Anderson et al., 2011; Snell et al., 2009; A. o. D. D. U.S. Department of Health and Human Services, President's Committee for People with Intellectual Disabilities, 2011; Yamaki & Fujiura, 2002). The living arrangements of interviewees appeared similar to the population. The majority of individuals (8) lived either with a family member or in a supervised setting (Stancliffe & Lakin, 2007). In the area of post-secondary education, for this sample, the percentage of persons enrolled in college courses (16%) was two times higher than reported by Anderson (2011) for the population of persons with mild intellectual disabilities. However, Anderson reported on those who completed courses, rather than only enrolled in college courses.

Also similar to the population of persons with mild intellectual disability was the undefined etiology of the disability for the majority of interviewees (Croen et al., 2001). Other than the three individuals who identified themselves with Down syndrome, interviewees were either vague or unaware of the reasons for their disability.

What is *atypical* about this sample is the level of advocacy work that some interviewees engage in compared to the at-large population of individuals with mild intellectual disability. Also in this sample, by nature of the recruiting process for the interviewees, everyone received support services as a result of their intellectual disability. However, many individuals with mild intellectual disabilities fall between the service cracks and do not receive the supports that others with more significant intellectual disabilities receive (Snell et al., 2009; Sullivan & Adock, 1999).

Table 3.1 Connection of Research Questions and Research Topics to Data and Data Collection Method

Research Questions	Data	Data Collection Method
<p>1. What experiences influence the formation of identity for sampled persons with mild intellectual disabilities?</p> <p>Topic: Influential experiences related to the formation of identity</p>	Narrative	Life story interview GBC
<p>2. What are the common themes that offer insight into the developmental processes that lead to</p> <p style="padding-left: 20px;">a. Communion</p> <p style="padding-left: 20px;">b. Agency</p> <p>Topic: Agency and communion</p>	Narrative	Life story interview
<p>3. Are there response patterns of similarity and difference within the sample?</p> <p>Topic: Agency and communion</p>	Narrative	Life story interview
<p>4. What are the common themes that offer insight into the developmental processes that lead to redemptive or contaminated story?</p> <p>Topic: Redemption and contamination</p>	Narrative	Life story interview
<p>5. Are there similar and different response patterns of redemptive and contaminated narrative story within the sample?</p> <p>Topic: Redemption and contamination</p>	Narrative	Life story interview

Table 3.1 (continued)

Research Questions	Data	Data Collection Method
6. How do the narrative themes of generativity and stagnation show themselves? Topic: Redemption and contamination; Generativity and stagnation	Narrative Numerical scores	Life story interview, LGS,GBC,SWLS
7. Are there response patterns of similarity and difference within the sample? Topic: Redemption and contamination; Generativity and stagnation	Narrative Numerical scores	Life story interview; LGS, GBC, SWLS
8. Are there other contributing factors in the identity making process that are not described by communion, agency, generativity or stagnation? If so, what? Topic: Influential experiences related to the formation of identity	Narrative	Life story interview Demographic Data Sheet
9. What is the influence, if any, of disability in the experiences of the sampled persons? Topic: Influence of disability on the formation of identity	Narrative	Life story interview
*LGS-Loyola Generativity Scale, GBC-Generative Behavior Checklist, SWLS-Satisfaction with Life Scale		

Table 3.2 Analytic Method for Answering Research Questions

Research Questions	Construct	Analytic Method for Construct Exploration (see Life Story Interview-Appendix A)
<p>1. What experiences influence the formation of identity for sampled persons with mild intellectual disabilities?</p> <p>Topic: Influential experiences related to the formation of identity</p>	<p>Formation of identity</p>	<p>Turning Point, Low Point, High Point, Earliest childhood, Other Significant Childhood, Wisdom, Future Scenes</p>
<p>2. What are the common themes that offer insight into the developmental processes that lead to</p> <p style="padding-left: 20px;">a) agency</p> <p style="padding-left: 20px;">b) communion</p> <p>Topic: Agency and Communion</p>	<p>Agency Communion</p>	<p>Turning Point, Low Point, High Point, Earliest Childhood, Other Significant Childhood, Future, Wisdom Scenes</p>
<p>3. Are there similar and different response patterns of communion and agency within the sample?</p> <p>Topic: Agency and Communion</p>	<p>Agency Communion</p>	<p>Turning Point, Low Point, High Point, Earliest Childhood, Other Significant Childhood, Future, Wisdom Scenes; Comparison of scores between groups per agency and communion themes</p>
<p>4. What are the common themes that offer insight into the developmental processes that lead to a</p>	<p>Redemption Contamination</p>	<p>High Point. Low Point, Turning Point, Wisdom, Adolescent, Religious/Spirituality Scenes, Use of data analysis notes, GBC, LGS, SWLS</p>

Table 3.2 (continued)

Research Questions	Construct	Analytic Method for Construct Exploration (see Life Story Interview-Appendix A)
a) redemptive narrative story, b) contaminated narrative story? Topic: Redemption and Contamination		
5. Are there similar and different response patterns of redemptive and contaminated narrative stories within the sample? Topic: Redemption and Contamination	Redemption Contamination	High Point, Low Point, Turning Point, Wisdom Scenes, Wisdom, Adolescent, Religious/Spirituality Scenes, GBC, LGS, SWLS, Use of data analysis notes; Comparison of scores between groups per agency and communion themes
6. How do the narrative themes of generativity and stagnation show themselves? Topic: Redemption and Contamination/Generativity and Stagnation	Generativity Stagnation	Wisdom Scene, Future Scene Use of data analysis notes, LGS, GBC, SWLS findings
7. Are there similar and different response patterns of the themes of generativity and stagnation within the sample? Topic: Redemption and Contamination/Generativity and Stagnation	Generativity Stagnation	Wisdom Scene, Future Scene, Use of data analysis notes, LGS, GBC, SWLS findings
8. Are there other contributing factors in the identity making process that are not described	Other factors in the identity making	Early childhood, adolescent, high point, low point, turning point; religious scenes, Use of data analysis

Table 3.2 (continued)

Research Questions	Construct	Analytic Method for Construct Exploration (see Life Story Interview-Appendix A)
by communion, agency, generativity, redemption, or contamination? Topic: Influential experiences related to the formation of identity	process	notes, agreement process method
9. What is the influence, if any, of disability in the experiences of the sampled persons? Topic: Influence of disability on the formation of identity	Lived experience of disability	High Point, Low Point, Turning Point, Wisdom, Earliest Childhood, Future Scenes, Use of data analysis notes, agreement process method,

Table 3.3 Group Selection Criteria

Group 1-Higher Generativity Individuals	Group 2- Lower Generativity Individuals
<ul style="list-style-type: none"> ○ Engages in community activities more than once in the past two months; (e.g. went to see a movie, ate dinner at a restaurant, attended a party outside of day program or home) (GBC) ○ Expresses concern for others (LGS) ○ Expresses interest in “leaving a mark” for future generations (LGS) ○ Has a history of being creative or is currently creative or involved in actions that show a concern for others (e.g. produced a piece of art or craft, advocacy, taught someone a new skills, volunteered, family involvement) (LGS) 	<ul style="list-style-type: none"> ○ Does not engage in community activities more than once in the past two months (e.g. went to see a movie, ate dinner at a restaurant, attended a party outside of day program or home) (GBC) ○ Does not consider self as active with others (GBC) ○ Is not currently creative or does not have a history of creativity or involvement in actions that show a concern for others (e.g. produced a piece of art or craft, advocacy, taught someone a new skills, volunteered, family involvement) (LGS)

Table 3.3 (continued)

Group 1-Higher Generativity Individuals	Group 2- Lower Generativity Individuals
Individuals must possess at least 3 of the 4 criteria for higher generativity or 2 of the 3 criteria of lower generativity for group assignment.	

Table 3.4 Group 1 Higher Generativity (LGS, 41.8 or higher; GBC, 29.6 or higher)

Name	LGS	GBC
1. Carl	57	42
2. Greg	60	41
3. Alice	58	50
4. Irene	39	42
5. Marlene	48	38
6. Otto	47	31
7. Vicki	40	40

Table 3.5 Group 2 Lower Generativity (LGS less than 41.8; GBC, less than 29.6)

Name	LGS	GBC
1. Andy	27	21
2. Ed	32	21
3. Kevin	36	12
4. Rose	29	6
5. Teri	28	11

Table 3.6 Summary of Research Process

Data Collected	Analytic Approach	Analytic Presentation
<p>Qualitative instrument</p> <ul style="list-style-type: none"> • Audio interviews; transcribed 	<ul style="list-style-type: none"> • Field observations • Respondent Validation Exercise (Bloor, 1978) • Data Reduction • Coding interviews- segmenting text (by units) • Second reader for coding reliability • Pattern codes/ Conceptual propositions • Individual case (Level 1) • Within group (Level 2) • Between groups (Level 3) 	<ul style="list-style-type: none"> • Narrative/Portrait • Vignettes • Tables for redemption, contamination, agency, communion themes

Table 3.6 (continued)

Data Collected	Analytic Approach	Analytic Presentation
<ul style="list-style-type: none"> • Quantitative instruments LGS; GBC; SWLS; demographic data sheet 	<ul style="list-style-type: none"> • Data reduction • Scoring • Individual composite of scores (LGS, GBC, SWLS) (Level 1) • Assignment of groups and comparison of scores within (Level 2) and between groups (Level 3) 	<ul style="list-style-type: none"> • Narrative report • Tables for LGS, GBC, SLWS; demographics

*The coding schedules used for the narratives (qualitative) provide quantitative data.

Table 3.7 Strategies for Managing Threats to Validity and Reliability (adapted from Miles & Huberman, 1994)

Threat Domain	Strategy	Stage
Cognitive limitations of interviewee: comprehension of questions, literacy (reliability/dependability)	Pretesting and adaptations of questions and available responses on similar population; interviewer skill of presenting material; asking person to restate questions; Interviewer to read questions and transcribe answers	<ul style="list-style-type: none"> • Prior to interview • During interview
Interviewee response pattern; concern for acquiescence (Reliability/dependability)	Use of open-ended questions, rephrasing and/or returning to questions, establishing environment of trust/relationship building, regard of the interviewee as 'expert'	<ul style="list-style-type: none"> • During interview
High attrition rate to scheduling, transportation, non-commitment (reliability/dependability)	Interview person at his/her place of convenience and time, volunteer basis, maintaining ongoing contact with person	<ul style="list-style-type: none"> • Prior to interview

Table 3.7 (continued)

Threat Domain	Strategy	Stage
Internal reliability & validity (dependability)	<p>Use of reliable and valid instruments (life story interview, LGS, GBC, SWLS)</p> <p>Use of thick description</p> <p>Check for internal consistency of interviewees story, across time, by episode</p> <p>Use of triangulation methods (qualitative, quantitative)</p> <p>Use of blind rater</p> <p>Researcher expertise/experience; review with committee co-chairs</p> <p>Methods and procedures described explicitly and in detail in reporting of research</p> <p>Study data retained and available for reanalysis by others</p> <p>Areas of uncertainty identified in discussion</p>	<ul style="list-style-type: none"> • Prior to interview • During data analysis
Inconsistency due to personal interpretation (reliability/dependability)	<p>Use of standardized materials, audiotaping, use of one interviewer for all interviews.</p> <p>High consistency between raters</p>	<ul style="list-style-type: none"> • Prior to interview • During data analysis

Table 3.7 (continued)

Threat Domain	Strategy	Stage
Inconsistency of analysis (reliability/dependability)	Use of interrater reliability, blind rating procedures	<ul style="list-style-type: none"> • During data analysis
Reliability of transcribed material (reliability/dependability)	Use of field journal/contact summary sheet for immediate impressions, researcher's notes	<ul style="list-style-type: none"> • During interview
Misunderstanding of interviewee (reliability/dependability)	Feedback from interviewee following write up of interview	<ul style="list-style-type: none"> • During data analysis
Sample selection (validity)	Purposive sampling	<ul style="list-style-type: none"> • Prior to interview
Are conclusions transferable to other contexts (external validity)	Characteristics of research sample described enough for adequate comparison to other samples. Discussion includes reporting of possible threats to generalizability Use of other findings in life story research for comparison	<ul style="list-style-type: none"> • During data analysis/ discussion

Table 3.8 Select Demographic Description of Interviewees

Participant Pseudonym	Age	Gender	Race	Religion and Level of Religious Activity	Primary Activity	Living Situation	Income Source	Marital Status	Number of children	Disability Causation
Ed	65	M	C	Christian-Fundamental-IA	Paid Work-Kitchen	Apartment Alone	Gov't benefits p/work	Single	None	I.D.-Unk.
Otto	65	M	C	Jewish-IA	Paid Work Advocacy	Supported Living with roommate		Single	None	I.D.-Unk.
Alice	63	F	C	Christian-Fundamental-A	Paid Work Advocacy	Home owner with sister	Work income	Single	None	I.D.-Brain Trauma-Early Childhood
Greg	61	M	C	Catholic-A	Vol. Work Advocacy	Apartment Alone	Gov't benefit	Single	4 (adult children)	I.D. & lower amputee-Unk.

Table 3.8 (continued)

Participant Pseudonym	Age	Gender	Race	Religion and Level of Religious Activity	Primary Activity	Living Situation	Income Source	Marital Status	Number of children	Disability Causation
Rose	56	F	C	Catholic/Jewish Active as Catholic	At Home	Supervised Living-Alone	Gov't benefit	Divorced	None	I.D.-Unk.
Kevin	44	M	B	None	Work-Paid and Unpaid-Kitchen	Apartment Alone	Gov't benefit, p/t work	Single	None	I.D.-Unk.
Andy	43	M	C	Catholic-A	Paid Work-Clerical	Supervised Apartment-Alone	Gov't benefit, p/t work	Single	None	I.D. Brain Trauma/spinal meningitis (3 yr.)
Vicki	43	F	C	Catholic-A	Paid Work-Clerical Advocacy	House with parents	Gov't benefit p/twork	Single	None	I.D. Down syndrome

Table 3.8 (continued)

Participant Pseudonym	Age	Gender	Race	Religion and Level of Religious Activity	Primary Activity	Living Situation	Income Source	Marital Status	Number of children	Disability Causation
Irene	39	F	B	Catholic Currently studying	On-line college, Paid work-Retail	Apartment Alone	Gov't benefit, partwork	Single	1	I.D.-Unk.
Teri	35	F	C	Presbyterian-A	College	Supported living with roommate	Gov't benefit	Single	None	I..D. Down syndrome
Carl	27	M	C	None	Unpaid vol.transition al program	House with family	Gov't benefit	Single	None	I.D. Down syndrome
Marlene	26	F	C	Quaker-A	Paid Work/Art Program	Supported living with 3 roommates	Gov't benefit, work stipend	Single	None	I.D.-Unk.

Single: never married; Supportive living: staff in home; Supervised apartment: staff available if needed; IA-inactive religion; A-Active

Table 3.9 Summary of Demographic Characteristics of Total Sample

Characteristic	N	%
Gender		
Male	6	50
Female	6	50
Ethnicity		
African-American	2	17
Caucasian	10	84
Marital Status		
Married	0	0
Single	11	92
Divorced	1	9
Living Situation		
Alone in community apt.	4	33
Alone in supervised apt.	2	17
Supported w/roommate(s)	3	25
Family/Parents	3	25
Primary activity *		
Paid work	7	58
Volunteer Work**1	4	33
Retired	1	9
Advocacy work	4	33
College	2	17
Income below the poverty threshold (household)	9	75
Active in Church	7	58
Number w/children	2	17
I.D. Disability/Causation		
Down syndrome	3	25

Table 3.9 (continued)

Characteristic	N	%
Early childhood brain trauma	2	17
Unknown	7	58

* Does not add up to 100%, individuals may be engaged in part-time paid and volunteer work.

** Volunteer also included one individual in a youth to adult transitional program, which involved volunteer work.

*** A specific question was not asked regarding income amounts but rather source of income, assumption made based on source

Chapter 4

Findings

Demographic Characteristics That Influence the Identity Making Process

Four demographic findings offer insight into the identity making influences. First, the demographics help frame a story about persons whose advocacy experiences influence the formation of identity. Four of the interviewees described themselves as active participants or leaders in the promotion of rights for vulnerable persons. Second, the level of church participation (58% of interviewees) indicates potential experiences that impact the formation of identity. Third, employment or other community engagement activities (volunteer, day program activities, post-secondary education) suggest important experiences that influence identity. Fourth, different experiences emerge from different living arrangements; some settings encourage more independence and adult learning experiences while others, such as living with family, may challenge the individual to assert her adult identity.

Four additional demographics serve as potentially contributing factors: age, gender, race/ethnicity and income status. Findings presented later in Chapter 4 explore the individual stories considering the impact of the variables of age, gender, ethnicity and income level. These variables are also considered in the group comparisons. Due to only two African Americans in the sample, the factor of race cannot be fully explored within the group context. However, the individual stories of these African-Americans do provide insight into how race influences the identity-making. Income status in many ways may influence the identity making process and this is explored later through individual portraits.

Portraits

This portrait section presents the qualitative and quantitative findings for each interview.⁵ In the fashion of the pen portraits discussed in the Chapter 3, a template is used to explore meaningful findings (Chapman, 2005; Dixon, Chapman, & Hill, 2005; Holley & Colyar, 2012; Howatson-Jones, 2001; Lawrence-Lightfoot, 2005; Lightfoot & Davis, 1997; Merrill & West, 2009) . Each portrait provides a narrative description, qualitative interpretation, and quantitative and qualitative scores derived from the Loyola Generativity Scale (LGS), Generativity Behavior

⁵ Pseudonyms are used for names of interviewees.

Checklist (GBC), Satisfaction with Life Scale (SWLS) and the McAdams' coding schedules for agency and communion and redemption and contamination.

The twelve portraits are sequenced by their placement in two groups, lower and higher generativity, which is explained and explored in detail in Section 3. Group 1, higher generativity, includes Carl, Irene, Greg, Alice, Marlene, Otto and Vicki. Group 2, lower generativity, includes Andy, Ed, Kevin, Teri, and Rose.

Higher Generativity Group

Carl Duggin

I met with Carl (Caucasian, age 27), the youngest male of the sample, at the agency which provided the referral. We met twice for a total of approximately 90 minutes. For his first interview Carl came dressed in a pressed red, white, and blue checkered shirt, saddle shoes, and khakis. At that interview he informed me that he was a Republican. Unlike others, Carl did not provide many details to his story, but rather narrated in broad sweeping story lines of achievement and status. He spoke in concrete terms and was direct in his answers.

Carl lived with his parents as well as his older sister and her family. He indicated that they were temporarily living in the parents' basement apartment. His schedule consisted of attending a transitional day program, described as (agency name) University, four days/week. He also attended the group's evening and weekend activities. Carl's great passion was sports and he assisted with coaching a local girl's 4th grade city-wide basketball team. The coach was also a staff member at his day program.

The original presentation of the interview format, i.e. imagining Carl's life as a movie, proved challenging for Carl. At times it was unclear if he described actual memories or if he invented stories that fit his internalized preferred identity. When in doubt about the veracity of the description or memory, I redirected Carl or asked for clarification. Whether the memories were actual events or embellishments of dreams, Carl's 'real' self and 'fantasy' self shared a consistency of themes, actions and beliefs. When asked to talk about what was the theme of his movie, he replied, "It's about, the movie is about me....Um, about dreams and goals and um, that's why, about my life". When asked what the title would be, he replied quickly with *Carl's Life*. He then paused and corrected this to *Carl Duggin's Life Story*, indicating an investment in the narration as well as thoughtful enthusiasm for taking this seriously.

Carl told his life story with enthusiasm and passion of a young man eager to tell his story and to take charge of his future. In Carl's transition program, he often volunteered in community efforts, such as those which supported U.S. military personnel.⁶ In addition to attending this program for ten years, Carl worked at a chain restaurant as a food preparer.

Although he considered this job as a significant life change story he emphasized that it was a job and not a career. Carl did not identify religion as a driving motivation or presence in his life, although he confidently stated, "I believe in God and Jesus. ... If I die, I go to Heaven". He stated that he infrequently attended the Catholic Church. When asked to describe a scene that would show his religion or spirituality, he described one in which he prayed in church for a "big basketball win".

Carl attended special education classes at the local public school. He stated that he attended special education classes exclusively in elementary school and only one special education class in high school, taking regular education classes for most of his subjects. Carl remembered his school years in a very active mode and centered on sports.

Interestingly, except for Carl's earliest childhood memory, his self-reported narrative did not include significant mention of his family; rather it focused on his past or current friends. When he did talk about his family it was frequently in the context of his sports' passion. Carl identified many peers in his transitional program as well as staff as important in his life.

As a young adult, Carl's social identity and personal identity centered on engagement with his peers and achieving success in his world of sports. His short-term goal was to "move out of the house" even if that meant moving to the basement of his parents' home. Carl was extremely focused on success; he was very clear about what he wanted and did not consider his disability (Down syndrome) a hindrance.

Portrait Specific Interpretation-Carl Duggin

Internal validity. As discussed earlier, the interviewer questioned Carl's understanding of the use of the movie metaphor for his life. Throughout the interview as a check for internal validity I asked Carl whether the story was his "real life" or "movie life".

⁶ Occurring post-interview, Carl was awarded a prestigious United Way volunteer award, confirming his story of significant community engagement.

Additionally, I repeated back to Carl what he thought was said, in order to confirm the story. For purposes of analysis only Carl's "real life" memories were included. However, Carl's "wished for" or imagined scenes were consistent with his overall identity and fit importantly into the coherence of Carl's life story. His imagination remained true to his sense of self and individual beliefs and values.

Interpreting the narrative. Carl primarily narrated his life story from an adolescent perspective. His idealized self, told through his imagined scenes, compared to other adolescents' dreams of fame and external recognition. In many ways, it appeared that Carl had 'bought the dream' of white middle class suburbia, attending a prestigious college, becoming a white-collar business man (sports business) and having a family. Carl's identity mirrored that of a typical adolescent within his socioeconomic class.

His memories and anticipated future were not tethered to an identity of a person with intellectual limitations. However, many of Carl's current non-family experiences occurred within the disability specific program and scored for agency and communion. He quickly answered what were the most important things in his life, as "(Name of program), family and friends. Friends are important because they're caring of me. From family the most important is love. And from (Name of program) it is love". Five out of seven of Carl's 'real' life sequences scored for communion.

For Carl, being a part of a group with peers with similar disabilities ranked as his high point. "(Name of program) is my life", (Name of program) is great for me, ...Name of program's) family." Carl's connection to this agency program was not only for his immediate friendships but spoke to a sense of belonging and of being something bigger than him, "I part, I'm in it." Carl's low point was the death of a friend whom he met at the agency. Overall, his stories focused on his sense of self in relation to his peers.

Carl's turning point scene illustrated an identity experience typical of adolescence (McAdams, 2009a). He scored highest in agency when he narrated his experience of working at a chain steak house. From this experience, he gained the insight that it "was good for me" and that he learned about food and that "I love myself." Equally important, he accepted the responsibility of holding a job while realizing that he did not want to make this a career. He gained from this experience an outlook on his future adult life and resultant identity.

Scores: LGS, GBC, SWLS. Carl scored higher on all three instruments, LGS, GBC and SWLS, than the sample averages. (See Table 4.1)

Scores: agency/communion. Contrary to the LGS, GBC, and SWLS scores, Carl's narrative contained fewer agency and communion themes than the overall sample. (Of interest, his imagined scenes scored a higher agency average [1.5] and a lower communion average [.5] than his 'real scenes'.) His most frequently narrated agency subtheme, achievement and responsibility, closely matched the frequency of the overall sample. The frequency of his communion subtheme, love and friendship was twice that of the overall sample. (See Table 4.1)

Scores: redemption/contamination. Carl's life story produced neither redemption nor contaminated stories.

Irene Jacobs

Irene (African-American, age 39) lived alone in an apartment in a large apartment complex. Dressed in a red ball cap, stretch pants and a tee-shirt, Irene welcomed me into her clean, sparsely furnished home and led me into her dining room where she sat in front of a laptop computer. She stated that she was finishing a college psychology assignment and would be done shortly. The interview, which lasted approximately ninety minutes, was frequently interrupted by phone calls both from and to her 19-year-old nephew and fiancé.

Initially, Irene was quiet but warmed up in the first few minutes. She demonstrated a concrete thinking process in the manner in which she answered questions. Irene talked openly about significant life events and they impacted her. I was struck by her sadness, evidenced by the tone of her voice and frequent sighs. However, except for a slight tearing up when talking about caring for her sister prior to her death, she emoted little affect. Two underlying emotions, sadness and determination, were evident both in the tone and in the details when she narrated her life story.

Irene had recently begun part-time work at a large discount store as a return assistant. In addition to her work income, Irene received government benefits based on her intellectual disability.

Regarding religion, Irene stated that she was baptized for the "first time" with her mother, brother and sister when she was sixteen or seventeen. At 39 years old, she believed, (that) now is the best time for me to start looking at going back to church. In my life now that I am older and since I'm getting ready to get married. Only thing with that is I have to... to

become Catholic because my fiancé is Catholic and I'm studying to be Catholic basically and that takes a lot to learn to be Catholic so.

Neither spirituality nor religion held a priority position in Irene's identity making process. When asked about her religious beliefs, she spoke of her religiosity instrumentally, rather than emotionally; religion was something to do to get to somewhere else, i.e. marriage.

Later, when specifically asked "(H)ow do you think God fits in your life?" Irene provided a spiritual meaning to her faith. "Uh, he has given me a great life and he's always been there when I needed to talk, and he been pretty much is looking after my sister now so." She continued,

Well, he wants me to be able to handle my life to the fullest and be able to know exactly how to live it and where I need – want to be and at least try to handle getting along with my mother pretty much, which it's – I'm trying but it's really kind of hard.

Even in this account, Irene offered a hands-off approach from God with an emphasis placed on her responsibility to manage her life. (And as frequently happened in the interview, the relationship between her and her mother took front stage.)

Irene valued education, despite the challenges that she faced related to her learning disabilities. She attended special education classes throughout her school years and spoke proudly about graduating from high school. Currently, she was studying at an on-line college with intent to graduate with a criminal justice degree. She recognized that her ADHD (her words) presented an academic challenge. Her interest in criminal justice originated from her deaf brother's negative experience with the police. Irene wanted to positively impact the criminal justice as it related to interacting with persons like her brother.

Irene's family served as a wellspring of confused emotions; of past and present anxiety, emotional pain and loyalty. Irene's early childhood narrative contained beginning elements of her identity making process of internalizing her life-long sense of responsibility for others and belief that she stood alone in caring for herself. She recalled in a memory at age five of not only having fun but

when I was little I learnt that I could do anything I set my mind to and I learnt to try to – at least try to be able to get along with other people to a certain point. But, its gets harder and harder as you grow up.

In recalling her childhood, Irene's silence on her mother's presence in her life was striking; suggesting her mother's emotional and physical absence. This theme of responsibility for her and others solidified during her high school years, when she cared for her sister during an extended illness resulting in death. Without emotion, Irene stated, "(B)asically, I took care of her, my sister, and just doing whatever needed to be done".

Nineteen years later, Irene continued to keep her promise to her sister, to watch after her nephews. She promised her sister, "that I would look after them (her nephews) and I am pretty much basically looking after them".

Seven years ago, Irene lost custody of her 4-year-old son to her mother. She described her son as a child with major learning problems who attended a special education program.

Irene met her fiancé on line. Much older than Irene, he lived in Michigan. They planned to marry in several months, against her mother's advice. Irene also considered Ted, the county board service facilitator, as the most positive person in her life.

Portrait Specific Interpretation – Irene Jacobs

Internal validity. At times when Irene appeared to have difficulty with rating her answers to the quantitative questionnaire, I repeated or rephrased the questions and then verified the answers with alternative wording.

Regarding the interview, Irene presented a coherent narrative. She narrated a congruency between her actions, beliefs, values and interpretation of her life experiences. However, due to her reticence to share her feelings, and the subtlety of her physical expressions, I questioned my accuracy in reading her emotions, such as, when she talked about her taking care of her sister and her son.

Interpreting the narrative. Irene traveled a life-long road to gain her mother's respect and love and ultimately to find herself worthy of self-respect and an identity of a competent adult who made wise life choices. She also internalized the strong message that one should become independent and self-reliant. However, as Irene became a young adult, her mother became a strong controlling force and undermined Irene's sense of competency and self-identity. Irene encapsulated her need for her mother's approval in her life story movie title, *How to get along with your parent-mother*. Her emotional and psychological turmoil surrounding her mother's approval exemplified the internal developmental tension of agency and communion.

Irene narrated a reoccurring theme of approaching life instrumentally, not emotionally. Irene made little mention of anyone's name, except for her son, in telling her stories. This lack of intimate naming confirmed a characteristic isolation woven throughout her story.

Lacking in Irene's key memories was an emotional attachment, vulnerability or positive relationship. Her personal identity rested on a sense of imposed responsibility and caretaking. In recalling the death of her sister as the lowest point of her life, she narrated this experience in terms of the events surrounding her sister's death and not her own feelings of loss. The interviewer acknowledged "that it is a sad time", to which Irene responded,

Yeah. It's like it's rough trying to do everything at once and then trying to get everything where it needs to be....And I've been – I've taken care of her. I also took care of my 19-year-old nephew, the 22-year-old and I'm basically now got my own.

Regarding how intellectual disability factored into her identity making process, Irene compartmentalized the difficulties that her intellectual disability posed for her. She accepted that deficits in problem solving and her limited abstract thinking ability posed a challenge to her educational goals. However, she did not generalize these cognitive challenges to her pattern of unhealthy relationship decisions.

Irene narrated a self-identity that included motivation to achieve something better for her. She imagined a brighter future for her and her son and actively took responsibility for achieving this. She challenged herself "to learn to arrange my life to where it needs to be and how to do things as it should be".

Scores: LGS, GBC, SWLS. On the LGS, Irene scored 39, placing her in the average sample score range. On the GBC, Irene scored higher than the overall sample average, however, she scored considerably lower on the SWLS than the overall sample. (See Table. 4.1)

Scores: agency/communion. Irene's scenes contained slightly less agency and communion themes than the overall sample averages. Irene's narrative contained less achievement and responsibility and more love and friendship than the overall sample. (See Table 4.1)

When anticipating her future story, Irene imagined: getting married, um [pause] living with my husband and my son. Um, just having a happy life and going on and doing things with my husband and my son. Going to the – taking my son to the beach and letting him get through school [pause] and letting him decide what he wants to do with

his life. Interviewer: How would that movie end? Irene: Um, [pause] my son growing up, getting through high – my boy in high school, graduating from high school, going to college, getting a degree, him having his own children and [pause] being - having – doing whatever he chooses to do with his life.

The prevailing theme of love and togetherness exuded from this scene. Only in the future did she anticipate a generative life. This generativity flowed from her son’s achievements and her son’s opportunity of “doing whatever he chooses to do with his life”.

Scores: redemption/contamination. Irene narrated one redemption story and no contamination story. (See Table 4.1) The content of her redemption story focused on personal growth, individuation and learning. As an adult, Irene learned more herself in the areas of health and intellectual disability. From this knowledge her behavior changed, as she described:

that now as an adult I think I’ve learned a lot of different things that I really didn’t even know. I learned how to keep up with my – learned how to control my disabilities, my – I learned how to control my health problems.

Greg Hill

I met Greg (Caucasian, age, 61) on two occasions at his home in one of the city’s poorest and most dangerous neighborhoods. He lived in an accessible one bedroom apartment in a building which appeared to be a cut-up large old home. An old wooden ramp, which allowed him to use his wheelchair, led into the hallway.

We met in his small front room, which was crowded with old furniture, appliances and wheelchairs. Occasionally, a friend came into the room with an old bone-bare pit bull. A noisy box fan made it difficult to hear Greg. After the first interview, I discovered that the sound of the fan often overwhelmed the recording and Greg agreed to a second interview for clarification purposes.

Greg narrated in a passionate story telling fashion. At times it was difficult to understand him due to his articulation. He displayed a sense of confidence, passion for his work and righteousness in his statements, with declarations, such as, “It’s something I love to do.” And “(N)ow I love my life, I don’t take my life.”

At the time of the interview, Greg was volunteering full-time, working with persons who were homeless. He also repaired small appliances for friends and neighbors. Greg's VA pension and Social Security Supplemental Insurance paid his expenses.⁷

Greg credited all good things in his life to God, including saving him from suicide and drug overdoses. For the past eight years, Greg attended weekly Mass at an inner-city parish, which ministered to the poor. In his own work with persons who were homeless, he believed that he lived his religion rather than preached it.

When asked directly about his education, in order to complete the demographics, he stated that he attended special education classes in Baltimore; but left at age 14 and in the 5th grade.⁸ He made no narrative reference to his schooling. Greg's life story, in total, included few close attachments. He rarely included names in his remembering. He considered his case manager a friend and worked with him on an agency committee focused on community inclusion. Others in his narrative included a "church woman, Millie", who saved his life at age eleven, a woman whom he helped become sober in the past year and a childhood friend, "Homer the Wino", a homeless man with whom he traveled and shared food. Throughout his story, he offered no reason for his parents' abandonment. When asked to name a hero, Greg cited "Boxcar Willie".

Given Greg's story of few friends or attachments, it was unexpected on the second interview that he reported, "I had a pretty good Father's Day." He shared that his daughter visited him, and that he had two daughters, two sons and three grandchildren.

Greg's point of reference for his social identity was "bum, hoboes, bag ladies or children", whom he called "Orphan Annies". Although, in his narration of his life story, he did not identify as a person with a disability; he committed to work that focused on creating an inclusive community.

⁷ In a collateral contact the case manager shared that Greg did not receive a VA pension but rather Social Security Disability benefits. The county board was unable to confirm that Greg was in the military. The case manager confirmed Greg's volunteer work and stated that he took in many homeless persons, assisting them to find more permanent housing.

⁸ Greg's case manager shared that Greg lived at a state developmental center between the ages of 15-28, when he was discharged in 1977. During his years there he ran away many times.

Portrait Specific Interpretation- Greg Hill

Internal validity. Greg's life story lacked an 'objective' confirmation to many of his personal memories. As noted above, official records did not confirm his military status, or his recount of living on the riverbank or on the railroad in his early years. However, his case manager confirmed that Greg lived without family attachments and in a large institution for individuals with intellectual disabilities. Greg retold this abandonment through his remembered past of living in poverty, in fear, and without the security of family.

Within his narrative of eleven scenes, Greg consistently recounted details of his life. For example, with the same clarity of detail he recalled his suicide attempts in two scenes, (childhood and religion/spirituality scenes). Additionally, at the second interview, Greg repeated the same stories and confirmed the previous week's details and chronology. Importantly for validation purposes, Greg's life story had an internal consistency from early childhood to his anticipated future.

Interpreting the narrative. Greg, from his early childhood to his imagined future scene, psychologically moved from fear and despair to redemption and generativity. The themes of his story parallel other redemption stories retold by persons who struggled with and survived alcoholism or drug addiction (McAdams, 2006b; Pals, 2006; Singer, 2001). Greg's mild intellectual disability appeared to have little impact on his self-identity; rather his self-making originated from a lifetime of past negative patterns of poverty, loss and lack of attachment. What he did not receive from others he drew from his faith. He credited his faith for his resiliency and redemption.

Also from this faith-based motivation, he sought to give back to those like himself. Greg's spiritual identity served as a connector of his self-interpretation of his past to the perceived personal identity and the generative actions of his present.

Greg lived his life using his strengths. Like other interviewees with mild intellectual disabilities, he adapted well to his socio/cultural environment and brought no attention to his impaired cognitive abilities.

Scores: LGS, GBC, SWLS. On the LGS, Greg scored at the highest end of the range of possible scores and exceeded the overall sample average. He also scored higher on the GBC than the overall sample and scored 5 out of 5 points on the SWLS. (See Table 4.1) Greg's scores placed him among the most generative interviewees.

Scores: agency/communion. Greg received the same score (.64 themes per scene) for communion and agency. These scores placed him below the overall sample average. Similar to the overall sample, Greg's two most frequent subthemes were agency achievement and responsibility and communion caring and help. His story revealed more of these themes (A/R and C/H) than the overall sample. (See Table 4.1)

Scores: redemption/contamination. Fifty percent of Greg's scenes classified as redemptive and one scene classified as contaminated. (See Table 4.1) Greg shared the highest frequency of redemption scenes with one other interviewee.

Greg's five redemption narratives included his low point, turning point, childhood, adult and spirituality scenes. Three recovery content themes, two growth content themes and one learning content theme appeared in the five scenes. In addition to the presence of a redemption theme, one scene contained enhanced communion and one scene contained enhanced agency.

In Greg's low point scene, he shared a history of early addiction (age 8) and late adulthood recovery. Greg, now in recovery for twenty-two years, shared that "I overdosed. I tried to kill myself twice".

Greg continued his redemption story when he described his turning point scene at age eleven. In this narrative, while he acknowledged the help of "a church woman, Millie" and other church people who helped persons at the riverbank and at the railroad tracks, he credited his own agency in his recovery process. He stated, "Now I love my life, I don't take my life." When asked what changed from addiction to recovery he answered, "Uh, I feel good about myself I quit".

Greg narrated in his third redemption scene that age nine, "I felt like there's nobody care about me," and "I tried to take my own life." When his drowning attempts failed, he realized that "God has a plan for me".

Greg's fourth scene occurred approximately four years ago, when "a church lady" asked him to name five good things about himself. This inquiry led Greg to positively reexamine his life and to enhance his work with drug addicts. His own growth and learning came as a result of understanding that one never gives up and that everyone has gifts.

Lastly, Greg's narrative concerning a religious or spiritual scene contained redemption. He again described how he twice overdosed at age nine and that God brought him back.

In summary, Greg's five redemption scenes consistently contained the theme that God saved him and that there was a plan for his life. His years of addiction and suicide attempts prepared him for his current work with persons who struggled with homelessness and addiction. Greg acted upon his generative beliefs, such as, God had a plan for him, and that he would give back to the world, in his current anti-homeless advocacy.

Greg narrated one contamination scene, which occurred in his adult life. This scene occurred when he gave money to a man who was a drug addict. Greg stated that he believed that it was a good idea to give him money but that it turned out badly, i.e. "he took the money and got high".

Alice Brown

Alice (Caucasian, age 63) and I met twice in her office for approximately two hours. I knew Alice by reputation, listening to her speak at several advocacy events and meeting multiple times at advocacy functions. I was hesitant at first to include her because of my familiarity with her. However, I did not know her life story, only her current accomplishments of her public speaking and advocacy work. As a group member during the initial phase of research preparation, Alice provided me feedback to my questions and recruitment suggestions. During one of those sessions, Alice offered to be interviewed, which I accepted a few months later.

Once in her brightly painted office, Alice showed me her numerous awards and butterfly mementoes on the walls. Alice spoke from a strong storytelling mode; she provided very visual and detailed descriptions about her life. Her stories were filled with emotion, pride and self-confidence, such as, "They all love me, "I got my voice back" or "I got the Power". She called herself a "butterfly superwoman", the meaning of which she detailed in her life story Alice possessed a professional persona of seriousness, deliberation and conviction.

Alice lived with her younger sister, Diana, in a home they purchased together. She considered Diana a constant source of refuge and support and credited Diana with helping her release guilt feelings connected to her inability to read. In the redemptive sequence about her inability to read, she quoted Diana as saying, "you don't have to read. It's not right. You don't have to feel so guilty 'cause you can't read it". Alice then added, "(A)nd I don't feel guilty anymore".

A striking theme in Alice's present story was that her work life was her life's work. She felt respected as a professional in the community and at her agency, where she had worked for 35

years. A few years ago, the agency formally recognized her community work and changed her title to advocate specialist. Currently, she worked four to five days per week in this capacity. Unlike the other interviewees, Alice received no disability related financial benefits, relying instead on her work income and sharing expenses with her sister. She expected to receive Social Security based on her age when she retired.

Alice identified herself as a key leader in the advocacy movement for individuals with intellectual disabilities, locally, regionally and nationally; serving as president in organizations such as, People First, and a member of the state Developmental Disability Council.

Another prominent life area for Alice included her spiritual and religious beliefs and activities. She was a devout member of a local Christian church and credited much to Jesus, including her ability to forgive. During a transformative weekend called the “Mass Walk” (sic), Alice released hurt and pain that she had held onto for many years. She credited Jesus for allowing her to let it go. “Anyway, I found Jesus on Saturday. I’m not going to say who, what happened because I don’t want nothing... something bad really happened to me and I couldn’t get over it for five years...”.

Alice’s belief in Jesus and the Christian principle of serving God in the service of others guided her daily life. Once a year, she completed mission work either in the states or in Central America. She funded her trips through her book sales and her sister’s fundraising efforts. The presence of Jesus occupied much of Alice’s narrative. For example, she provided this description of how she prepared for a public talk:

When I’m in the shower, I say my prayers...I sing a song. Always “Jesus Loves Me”, “Kumbaya”, and “Here I am Lord”, and “Amen”. They all, they all come out like that. And then I, when I get to the meeting, of where I gonna talk. Then I will have a moment for myself. And I will pray to Jesus.... And I will say, “put the words in my mouth, what You want me to say”. And then when I do it, it comes out.

In addition to her Christian beliefs, Alice described herself as a spiritualist, a quality that her grandmother possessed.

I have a grandmother. Well, I did have a grandmother, who was a spiritualist, you hear about that? ... She read people’s hands. ... Not a fortune teller, but a spiritualist... And she can read your palm and tell you what you’re going to be in two years. I have her in me. ... It’s a funny thing; her and I never talked about that. When I lived by myself,

before Mom and Dad died, she would come to me almost every night. A lot. Since Mom and Dad died, she don't come. But Mom and Dad's death comes to me. I would find them in different places in my health.... Interviewer: Mm-hmm. And do you actually see them? But you just feel their presence? Alice: No. I know what they do. ...Mm-hmm, but we [referring to her Grandmother] never talked about it. I mean, her and I were, when I was little and she was alive. I remember the time when she lived in Florida and before she died. She took Diana and Sally [Alice's sisters] in the back yard, and I know I'm not allowed.... So I know I'm not allowed to go back there, because I had a disability. Interviewer: ...Do you feel like you could read the future? Alice: I do. I do, I do have times I know it's going to happen, and this was before Andy [Alice's nephew] died. I woke up many nights with a gun, with a rifle in my hand, and Andy's name always came up.

Andy died from an accidental shooting by a neighbor boy, a tragedy that Alice believed she experienced as a premonition. Her premonitions also gave her additional power to reassure persons close to her that things will get better or the ability to warn about future problems.

And I said to Sally, I said, you watch Ted [another nephew]. It ain't going to be his, it ain't going to be his fault, but he's going to be in the middle of it. I said watch him. And that's the only thing I could say, and she believed me. I can say stuff like that. I know it's going to happen. ...like if somebody gets hurt, I can say to you, you're going to be alright and you're going to get better. And I think, I think that helped me when I had cancer. I had cancer five years ago.

When discussing her school years, she remembered:

when I went to school I hated it. I hated school. Because they didn't know how to deal with people having disabilities. But when I got in high school and I had my teacher named Jim, I could wake up, I couldn't wait to go to school every year.

Alice attended self-contained special education classes throughout her public school experience and she expressed great pride in graduating from high school. As an adult, Alice graduated from an intensive several month disability advocacy focused program, called *Partners in Policy Making*.

Family and friends figured significantly in Alice's life, with many memories including those close to her, such as the transformative Emmaus Walk, described earlier, her diagnosis of cancer and attending her high school prom. Scenes in which she included friends and family frequently scored both communion and agency themes, suggesting a balance between the two life themes. For example, in the past, Diana frequently accompanied Alice to important meetings and provided emotional support as well as material help, such as, transportation. This relationship opened the possibility for Alice to achieve recognition as well as positively impact the disability community. More recently, it appeared that Diana and Alice had transitioned into a more sisterly role than caregiver role, in many ways equalizing this relationship.

Alice enjoyed a strong support network beyond her family. She identified May, a younger woman with a learning disability, as her closest friend. She also considered herself May's mentor. In response to the question, what is a memory of showing or sharing wisdom, Alice offered:

My wisdom, when I talk to May, I tell her a lot of stuff. ... I think I tell a lot of the wisdom I want her to know, what I want her to learn. It's funny because she is 34 and I'm 63. It's much different ages.

When asked what her many friends have in common, without hesitation she declared, "they all love me."

Portrait Specific Interpretation- Alice Brown

Internal validity. Alice's interview was conducted over two sessions, lasting approximately two hours total. To verify the validity of the content from the first session, we reviewed the scenes and allowed for additional explanation. Alice was consistent in her memory of the described scenes. Throughout the two sessions, Alice repeatedly narrated her memories with theme consistency as well as "factual detail", such as time and place. Aware of my potential bias due to knowing Alice by reputation, I dutifully kept to the interview questions.

Interpreting the narrative. Alice emphatically stated her identity as the "Butterfly Lady" or "Butterfly Superwoman". Using this metaphor, she defined herself using the transformative life cycle of a butterfly. Her life embodied the life cycle of the chrysalis transforming into a complete and strong, free moving butterfly. In her public talks she described this as her transformation into realizing her own power and encouraged others to find their own internal power.

In the course of two interviews detailing her life story, Alice spoke the word “power”, 35 times, often multiple times in one sequence. Clearly, personal power, a sense of agency, occupied a huge psychological space in Alice’s life. She equated wisdom with having “the power” and felt morally obligated to pass on this wisdom and power to others, particularly to those persons with disabilities.

When asked how she would show your wisdom as a movie scene, Alice answered, “I would have to say it’s my power”. When asked to elaborate she continued, “I say the power a lot of times. And anything I’ve work for, do anything, is sort of picture I always put there”.

In this sequence, Alice described her picture on the last page of her published book of stories.

My last page for me was a thumbs up. ...And I say that I’ve got the power... .Well that means a lot to me. I don’t think people who have a disability, if they can’t have power or they don’t feel power, they don’t know what to do with that... Like, I can do that because I’ve got the power. I can do that, whatever, that is because I have the power. ...And to get the power, it taken a long time to get that. When I was in a cocoon, I would not say I got the power.

The strong generative theme to her identity revealed itself in her explanation of guiding others to find their power. Her “power” was her gift to share. When asked what she shared with May that reflected her wisdom, Alice replied, “I share my love to her. And I tell her what people should do. And when I talk to people, I never leave anybody out... And that why I love to go places, teach people the wisdom”.

Another powerful theme evidenced in Alice’s narrative was her adaptability and flexibility. Like a butterfly, she changed her direction according to life’s wind currents while she maintained wholeness to her sense of identity. She learned to be kind to herself, such as, no longer feeling guilty about her inability to read. She adapted her personality to accept challenges, such as, presenting to large audiences or to government committees, by memorizing her material, rather than relying on someone reading for her. She accepted her challenges posed by her cognitive abilities and the necessary requirements in a professional world. Her personal ideology reflected a humanistic dimension. Alice’s dispositional trait of openness to experience and flexibility stood as evidence to McAdams’ finding (McAdams et al., 2004) that highly

generative people possess a sense of adaptability and flexibility and are satisfied with their lives. In Alice's words, "you cannot gnaw on something you lost".

The last major theme for Alice spoke to her strong sense of spirituality. She took strength from her identity as a "spiritualist" and the carrier of her grandmother's prescient abilities. She continued as the holder of this family gift and believed that she positively shared it. Alice's strong Christian beliefs and resultant actions, i.e. "doing God's work", also grounded her spiritual identity. She felt a generative calling for purposive activity, which she regarded as teaching the work of Jesus, as she stated, "...do all you want to do, before Jesus says it's time". She believed that in her limited time on earth it was her purpose to do all that she could to help others find their power. Importantly, Alice also foresaw her work as continuing in Heaven.

Alice possessed a strong sense of personal identity; she lived out her beliefs by her actions that in turn reinforced her confidence and life purpose. Integral to Alice's identity was her taking claim of her intellectual disability. This recognition occupied psychosocial spaces in many parts of her life. She recognized this in her earliest memory when she stated that at age 5, "...I got my voice back." Alice was not sure how she developed a disability, but knew that it came after birth and that her brain was damaged. (See Redemption/Contamination section) She adapted to her challenges, such as telling time or reading, in ways that encouraged her independence and made her less "visible" as having a disability. She stated that, "I learned to be very patient [with myself]". Like others interviewed, Alice acknowledged the tension of being invisible to others in terms of having a disability, yet not always capable of meeting expectations,

My disability came after I was born. I don't have like May had that disability when she was born. Well I don't have that. And sometimes that bothered me because I always said this, if me, and Billy, Bill walking down the street, who will you see first? [Bill used a wheelchair.]

Scores: LGS, GBC, SWLS. Alice scored higher on all three instruments, LGS, GBC and SWLS, than the sample averages. (See Table 4.1) Alice scored the highest of all interviewees for the GBC and was one of 3 interviewees who scored the maximum (5) on the SWLS.

Scores: agency/communion. Alice's narrative was rich in agency and communion themes, almost twice that of the overall sample. (See Table 4.1) Her scenes contained more

agency and communion themes per scene than any other interviewee. Alice's most frequent agency subtheme, self-insight, was atypical for the total sample, whose most frequent subtheme was achievement and responsibility. Her most frequent communion subtheme (love and friendship) also scored higher than the total sample. (See Table 4.1)

Scores: redemption/contamination. Alice's life story produced four redemption scenes and no contamination scenes from the total 14 scenes scored. (See Table 4.1) In addition to four points for each scene she scored an additional three points for the categories of ultimate concern (1) and enhanced agency (2). The content of Alice's redemption narrative included growth and recovery subthemes. Alice's redemption scenes occurred during her earliest memory, turning point, wisdom scene and an additional scene centered on her struggle with a cancer diagnosis and treatment.

Alice narrated her earliest childhood memory as a redemptive scene. She vividly remembered saying her first words at age five with her speech therapist, Connie.

When I said dad the first time.... I couldn't talk for a long time. ...I don't remember the whole story about that...because I was little... But I remember going to this class when I was five. And it was a speaking class to learn how to speak.

Alice did not know the exact cause of her current disability. She explained:

(s)ee I was not born with a disability. My disability came after I was born.... (t)he only thing I can tell you is where my side, where my brain on one side is damaged. I had a fever or someone dropped me. We don't know.

She described this memory as significant to her life story because "...I got my voice back". This narrative, of finding her voice, resonated throughout her life. Having a voice signified for Alice a tremendous sense of power in how she lived and how she was perceived (heard/seen) by others. Having a voice provided a sense of mastery for herself and as she perceived it, for others with disabilities. In telling this memory, she invited the listener to witness this rebirth through her vivid visual description of her speech therapist, "she had a rope around her belt. Her belt was a rope. That's all I remember of that. Her hair was long, brown. She wore a rope around her belt." One senses the fascination of five-year-old Alice looking at the rope belt. She remembered feeling "really good. I then learned how to talk after that".

This memory began the powerful reoccurring metaphor of having a voice and power. Alice recounted that her speech articulation problems used to prevent her from saying what she wanted, but “(N)ot now. Before it did, but not now”.

The second redemptive scene occurred in Alice’s recall of a turning point. In this scene, she recounted her transformative weekend retreat, the Emmaus Walk. She framed her turning point scene from a redemption perspective, with the content evidencing a growth subtheme. She considered this a key change moment in her life in which standing at the alter she relinquished emotional pain, partook in the fellowship communion ritual and “found Jesus”.

Similar to her turning point scene, Alice described her wisdom scene also with redemption content. In her wisdom scene, she talked about another transformative or redemptive moment, which occurred at church. She recalled:

One time I was in Church, where I used to go, and my two sisters, we all went there together... And they were talking about people who have gifts, and I looked around to everybody and I realized I didn’t have a gift... at that moment. And I came back crying, and I went to my friend and I cried on her shoulder... And I cried. I didn’t have the power. I didn’t have no gifts.

As the church members surrounded her the moment transformed from negative to redemptive. She remembered that her friends told her, “yes, you do have gifts.” And she continued her recall:

That will never happen to me again, because I know I’ve got the gifts. Gifts is wisdom... If you don’t have a gift, you lost, because you don’t know what to do next. I think that’s why a lot of people are dying, get killed, because they don’t have that. They don’t have that. They can’t go past that. They can’t go past that, not having the power. They don’t know what power is.

Alice moved from a state of despair, feeling that she was worthless, to a state of feeling powerful and competent. She realized that this recognition of having “power” was the difference between living and dying.

While not explicitly identifying the cause of her enlightenment, the context of the story was one of religious conversion and the power Christian fellowship. As with Alice’s other redemptive scenes, the central content was one of psychological growth. She felt fulfilled and strengthened in her sense of power as well as communion with her fellow Christians.

Alice used the words wisdom and power interchangeably, linking both with a sense of living for the betterment of others. From this perspective this redemptive narrative scored a point for ultimate concern. She declared, “Now I would love to go, my wisdom would love to be on some kind of team and get rid of all the guns.” She chose this goal because of her nephew’s gun related death.

Scored also for redemption was Alice’s narrative of struggling with the diagnosis of cancer and subsequent treatment. Starting from the negative, she declared, “(Y)ou never want cancer”. Now in remission, she received her diagnosis approximately five years prior the interview and underwent several rounds of chemotherapy and radiation. Similar to many survivors, Alice found the treatment the worst part of having cancer. Alice, “(T)he cancer is not... the cancer ain’t bad. It’s where you have to go through it to get better. Interviewer: The treatment? Alice: Yes. That is bad.”

Alice moved through this initial state of pain into a positive state of leaning something about herself. “I learned very patience. You have to be very patient to go through cancer ‘cause cancer will ruin your mind for a while.” She credited her sister, Jesus, and her deceased grandmother with helping her move out of the fear and pain.

And Diana was there. Diana helped me a lot, because she knew I didn’t feel good. And so, I think I had all that. I think Jesus was there and my grandmother was there to help me through the things I went through.

Alice gathered her all her supports, spiritual and familial to move through the pain and fear. In addition to learning to be patient, she stated that she learned that, “I still got the power”. We again hear the recurring theme in her life story- having a voice and having power. The content of the redemptive scene was one of recovery. Alice successfully obtained her positive state of “having power” and returning to her self-advocacy efforts, following her recovery. The regaining of personal power led to interpersonal growth and a stronger sense of agency, having conquered cancer. Alice scored an additional point for enhanced agency because she not only learned to be patient with herself but also achieved a significant realization that she has “the power”.

Marlene Newcomb

I interviewed Marlene (Caucasian, age 26) for approximately 90 minutes one evening in her home. Marlene, a small woman with round wire rimmed glasses, shared her home with three

women also with intellectual disabilities. She referred to her housemates as friends and spoke positively about the 24-hour staff. At the time of the interview, her housemates were out of the house, participating in a writing group.

Their large ranch house fit in the middle class neighborhood and bore no identification as an “agency home”. The inside was bright and decorated with photographs of world travels and original artwork. After a tour of the first floor, we settled into the large living room. Marlene requested that the staff stay in the room; frequently dozing, the staff did not participate in the life story interview but assisted Marlene with the answering the Generative Behavior Checklist, offering Marlene reminders about activities in which she participated.

Marlene’s reflections, such as when talking about her teaching and artwork signaled a self-confidence and thoughtfulness. She stated that her teaching was “rewarding” and “...I feel best when I can actually teach what I’m making money off of.” She frequently incorporated book or movie references when talking about her life. She was clear in speech as well as meaning. She was amusingly self-deprecating, for example, laughing at her need for an “attitude change.” Her eye contact with me came during the times that I complimented her.

Marlene’s story telling was not linear but rather skipped from topic to topic. However, upon close listening, I understood her pattern of thought and picked out the dominating theme that carried her to a different content area. Her story telling was emotionally moved along through expressions of self-pride, eagerness and hopefulness. Marlene’s most common affects were determination and hopefulness.

Regarding work, Marlene received a teaching stipend from a local arts organization that supported artists with disabilities. Attending the program four days a week, Marlene also sold her artwork, which she created in the organization’s studio. , She co-teaches with the staff at a private school for students of all ages with autism. In addition to her teaching stipend, Marlene financially supported herself with Social Security Disability benefits. Marlene considered her experience at this arts organization as a high point in her life. As she described this experience:

That where I teach, um, I got a job with Kim [teaching staff], um, teaching kids with autism, um, the highpoint was, um, well, basically when I started, and I consider it as a highpoint as some of the people, there I see in myself and it’s rewarding to teach art to different people. And, and I feel best when I can actually teach what I’m making money off of.

Marlene's spiritual life reflected her religious upbringing. Raised as a Quaker, and attending meetings once or twice a month, Marlene followed its tenets, such as her opposition to war and doing "Jesus' work". Marlene also embraced the openness of the Quakers, "...really what the Quakers seem to do is like, they look past like barriers....The barriers would be skin color, different religion, um, or like, or like different, um background". This openness extended into her larger life story of exploring and understanding persons who were different from her, such as religion or race.

The events of September 11, 2011 initiated self-exploration and behavior changes for Marlene. For her generation this signified a watershed event. She recalled her "shock", but rather than retreating into fear and/or hate, Marlene accepted the challenge to learn about Muslims, and found a commonality with them.

In her more formal educational experiences, Marlene attended public schools in three states and received individual tutoring in academic subjects. Throughout the telling of her life story, Marlene consistently described a pattern of motivation and achievement in academic as well as personal goals. She remembered her high school years as positive as she described her friendships and involvement in sports. Following graduation, Marlene participated in a youth to adulthood transitional work program in which she explored different careers. She described one of her favorable experiences when she worked on a university campus, doing various clerical tasks. She related that although she did not attend classes, she "felt" like a college student.

Marlene was the oldest of three sisters. Her parents (separated) lived in Canada. Due to her father's work as a chemical engineer, the family moved around the country. Marlene's mother now works as an office assistant, and it did not go unnoticed by Marlene that she and her mother shared a common office work history, i.e. clerical work- "just like I did".

Throughout Marlene's life story, she referred to the sharing of the love of books and art with other family members, particularly her grandmother. She recalled stories of sisterly jealousy and cruel words from her youngest sister; her sister called her "mentally retarded". Presently, Marlene considers the house manager as a key mentor and support for her. She stated:

she's made me realize so much in my life, um and she wants us to be the best that we can be, even if we don't want that at the time. But I wasn't really all that into like having to cook for myself and clean up, um. But every time, I would do it and it just felt so great.

...When I finally learned to do stuff for myself. And I wasn't being dependent like a child.

Socially, Marlene pursued a number of activities which nurtured her mind and body. Until recently, she participated in a writing group for young women with intellectual disabilities. The group, facilitated by a local women's writing group, encouraged Marlene's love of words and story telling. Her short stories were included in a book published by this group. Marlene also participated in organized recreational activities two evenings a month at local non-profit agency for individuals with disabilities, participated in Special Olympics and took piano lessons.

Portrait Specific Interpretation-Marlene Newcomb

Internal validity. Marlene's manner of telling her life story made the theme of her narrative clear. Her themes of generativity, redemption and growth reoccurred with a consistency that provided predictability to her overall life story.

Interpreting the narrative. Overall Marlene's interview painted a portrait of a young woman who readily accepted the challenge of becoming independent and creating an adult identity. She was extremely open to change and acted upon this desire to be a more insightful and actualized individual. Her firm sense of spirituality showed itself in her quest for discovery and acceptance of those different from herself. She displayed great self-motivation and generativity in her thinking and actions. Marlene took advantage of many support systems throughout her life which allowed her to participate in a rich assortment of community experiences, including sports, religion, and cultural activities. Her life was characterized as accepting the challenge of change. This is what mattered to Marlene.

Marlene's life story reflected a generative disability narrative. Marlene seldom explicitly referenced her disability, which she described due to failure to thrive and seizures. However, she realized in her childhood that she was different. Her childhood and adolescent narrative included her inability to make the school soccer team, the necessity for individual tutoring, and extra support to transition from high school to work. Significantly, she and her family acknowledged her difference in positive ways, such as, playing on a community sponsored Top Soccer team, which did not require competitive capabilities but recognized the importance of team sports to a young girl's social and personal identity. Perhaps equally important, within the social geography of a middle class suburban community, Marlene (and her parents) maintained their social identity

as a “typical” family. Marlene’s perceived difference was also highlighted in negative ways, as in the case of an angry sister calling Marlene mentally retarded.

Multiple job experiences spoke to her motivation for a career; to be agentic. Marlene felt proud of her work as an artist and teacher; two factors that no doubt carried status and currency in her family.

In keeping with Marlene’s love for the literary word, which was fostered by her family, she employed her knowledge of literary works as a comparison for her struggles. Her personal narrative began as a story of failure to thrive, which she compared to Turtle, the infant in the strongly feminist book, *The Bean Trees*, by Barbara Kingsolver (1998). Turtle’s narrative suggested a child who was considered “retarded” because of her quietness and “otherness”. She was an abused Cherokee infant, given to the protagonist, by her mother who wanted more for her than she could offer. Turtle, different from the beginning, eventually thrived. Marlene, whose life started as failure to thrive, experiencing seizure and being considered ‘mentally retarded’ found psychological camaraderie with Turtle.

In addition to sharing her family’s love for books, she successfully embraced the family’s proclivity for creativity in the visual arts. Carrying on the family tradition and taking her gifts to the educational (special education) community, Marlene practiced her generativity through her own art and teaching responsibilities. Notably, these identity-making activities were experienced within the disability community.

Marlene wisely understood her narrative position when she commented that:

People with disabilities can do what they want to. It just takes a little bit more time to like, get into them and like, to realize, fine, um, and then and, ...it doesn’t really help to laugh at different disabilities than you because they could be the best, of, um, friends and you could end up learning from them.

Although Marlene psychologically embraced the primary community in which she participated, finding commonality with persons with different disabilities; her identity stepped beyond that of *only* a person with a disability. She placed herself in the larger progressive cultural community of understanding and appreciating differences between religions and races. Marlene possessed not only the dispositional trait of openness to change but what McAdams (2006b) referred to as “preference to conceptual complexity” (p. 284). This trait also gave impetus to her quest for personal growth and understanding as evidenced by her seeking

psychological counseling. She pushed herself to take risks with the goal of becoming a creative, caring and productive adult.

Scores: LGS, GBC, SWLS. On the two measurements, the LGS and the GBC Marlene scored higher than the total sample average. (See Table 4.1) On the SWLS Marlene scored a 4 which closely matched the total sample average of 4.02.

Scores: agency/ communion. Marlene's scenes contained 75% more agency themes than the overall sample, while her scenes carried 14% less communion themes than the overall sample. (See Table 4.1) Marlene's two most frequent subthemes were agency achievement and responsibility (47%) and communion unity and togetherness (54%). Her narrative contained slightly less achievement and responsibility and more than twice the unity and togetherness than the overall sample. (See Table 4.1)

Scores: redemption/contamination. From a total of 14 scenes, Marlene's life story scored six points for four redemption sequences. She constructed the following scenes as redemptive: low point scene, two turning point scenes, and spiritual/religious scene.

In Marlene's low point scene, the death of her grandmother inspired her to continue along the generative path of creating and teaching art. As she stated: "... And I just decided I'd move on and I'd do my artwork a little bit better to like, I don't know, preserve some of that, that I see, that I saw in Grandma".

The content of this redemption scene bore witness to Marlene's psychological growth and her inner drive for an adult identity. This wished for identity was in keeping with her grandmother's identity as an artist and the family's prioritizing a creative self.

A second redemption scene occurred during one of Marlene's turning point memories. In this scene, she described the positive change in her life when she moved out her mother's apartment into her present home. At her mother's home she felt that she was in a protected, albeit, emotionally difficult space. She related that: "... It was just, that it was time for me to move...".

Marlene exquisitely articulated the outcome of her physical move from a cramped apartment with her sister and mother to larger home with three roommates and staff. This physical move brought with it a psychologically larger positive space that offered a life "that I saw in the future". During the interview, Marlene nodded in affirmation when asked "so it was a move into adulthood?"

In Marlene's third redemption scene she initiated counseling after she recognized the need for a more psychologically healthy life. During this time, she experienced probable panic attacks that limited her physical movement as well as psychological/emotional movement into adulthood. She stated, "(B)ut, but then, um, I think the turning point, the real life change, was, um, the events that led up to seeing a counselor". Her emotional state prevented her from plane travel and kept her in a state of disorganization. Her movement toward personal growth signified this story's content. When asked what she thought that this scene said about her she answered:

It says that I wanted the change, that I was willing to change, um that I wanted to do anything that I could to have a job and if it meant a little attitude change [laughs] that was really what I wanted I think and I will keep on moving forward, um although it was scary change again because I didn't really know the counselor that I was doing (sic), but yet it made a really positive one because I made a step in the change for myself so that I would get a job.

By challenging herself to change and assuming personal responsibility for an 'attitude change', despite feeling afraid, she recognized that she could move closer to her goal of obtaining a job and establishing a career- major life events that promoted an adult identity.

Reflecting on the defining single event of her generational cohort, Marlene identified her final redemptive scene. She recalled watching, with friends, the plane crashing into the World Trade Center.

Um, I met them when I was 16 um, it was in the midst of um, of the shock of 9-11, basically, when I, when I looked at that TV screen, I kept on looking at my friends like, is this really happening? Somebody's really bombing an airplane into, into New York? I, I didn't think it was, possible but they said, don't look at me stare back at that screen because it's everything on there...But I couldn't believe it! I was so shocked! But basically, um, Usar, and Tina, and Melanie, were um, good helps, just as shocked as I was.

Out of this shock came a personal calling of "getting to know some of the people of different religions and faiths". She began to appreciate the nuances of religions, such as Muslims being "a peaceful group of people" and "that much (of) their faith is kind of like ours" (referring to Protestants). As a movie scene, Marlene envisioned this recollection as "sort of

quest for...learning”. From this tragedy, adolescent Marlene again challenged herself toward personal growth, this time in moral development.

Marlene shaped her understanding of September 11th events in terms of spirituality and religion. She searched for the commonalities in humanity rather than the differences. Her initial feeling was shock at the horror of what one group of people could do to others. However, rather than holding on to that negativity, she regarded this as an opportunity to learn and ultimately gain a self-awareness that Jesus’ teachings of peace and love were shared by non-Christians. This transformative event provided her an entrance into the larger moral world of ultimate concern.

Otto Pearson

Otto (Caucasian, age 65) and I met twice for a total of approximately 3 ½ hours. During our first meeting we met in his home, which he shared with another man with an intellectual disability. Otto stated that he moved to his current home almost six months earlier and that he and his roommate shared in-home agency help. For our second interview, Otto requested that we talk over lunch at a neighborhood deli. Upon entering, it was clear that the staff knew and liked him.

Otto spoke with authority and verbosity; he was a natural storyteller. During our conversation, Otto spoke openly about his life. Additionally, he shared a book on the early county history of services for persons with developmental disabilities. His mother figured prominently in this history and Otto considered himself successor to the mission of achieving community inclusion and quality services for individuals with disabilities. Otto frequently asked “you know what I mean?” He wanted assurance that I understood him and grasped the importance of his story. Similar to Alice’s narrative, he exhibited pride in being “the first”, for example the first person with an intellectual disability awarded guardianship of a family member or achieving recognition. Describing state officials attending his brother’s funeral, he hypothesized that they attended, “ become of me, not because of him (his brother)”. Throughout the interview, Otto displayed enthusiasm about the topic and confidence in his ability to tell his story.

Of note, Otto stated that others had interviewed him about his life story⁹. For our interview, Otto exhibited a gentlemanly politeness such as, holding doors for me and waiting for me to order first.

After completing the initial demographic information, we discussed Otto's work status. He described himself as retired but working part-time. He perceived this forced retirement, approximately nine months prior to the interview, as a turning point in his life. Otto had worked as a self-advocate for several years for a non-profit advocacy agency. Reflecting on this unplanned termination, he stated, "... I asked myself what am I going to be doing with myself". He added that he had been "laid off or fired from many, many, many companies" but this change affected him more deeply. In retrospect, he stated that the change was "some ways good, some ways bad". He currently enjoyed his advocacy work with the county DDS Board and stated that "I did good", but found himself "watching the idiot box [TV] too much". In addition to his work income, Otto received disability income from Social Security.

Regarding religion, Otto identified himself as a Jew. Many of Otto's notable life experiences revolved around his religion, such as his memory of his Bar Mitzvah as his first turning point scene. This experience, also narrated with redemption content and discussed at length in a later section, highlighted an ongoing challenge to educate the religious community about persons with intellectual disabilities. Reflecting on the meaning of the Bar Mitzvah, he spoke with pride about resisting the Rabbi's attempts to disallow him an adult Jewish identity. As he declared, "(Y)ou're supposed to be a man at 13 years old". A similar opportunity to educate this community occurred later when he assisted with the establishment of a program that provided religious/social activities for Jewish young adults with disabilities.

Otto's family circumstances heavily influenced his life experiences. Otto was the younger of two; his brother, Theo, several years older, was born with significant cognitive disabilities. Otto described Theo as having an "IQ of a three year old". Theo lived with his family, until age 13, when his parents placed him in state institution for persons with mental retardation (sic). This

⁹ Footnote - I later found reference to Otto's involvement with an oral history of self-advocacy leaders projected at the University of Illinois at Chicago, Department of Disability of Human Development. Otto's transcript for this project is archived at the University of Berkeley's Bancroft Library.

emotionally difficult move resulted from the accusations of a neighbor child that Theo just touched her as well as “just everything”, as Otto explained. Otto denied these accusations citing his brother’s significant physical and mental disabilities.

He argued that “...he could not pick up a dime...mentality of a three year old”. Otto, remembered these visits to the institution with great detail. Assuming a collective family responsibility (even though Otto was still quite young), he remembered, “We put him in the (state) Institution...1955 to about the late 80’s. ...I hated that. Going up there, seeing-looking at the window and seeing my brother through a window...through bars”.

After the death of his parents, Otto, in his late 30’s, assumed his mother’s advocacy caretaking role to ensure that Theo received the best possible care; and he moved Theo to a smaller institution closer to home. He declared that “I went there and saw the place [the new residence]. They didn’t like me...Because you seem like another handicapped person...a disability person... person taking care of your own brother...” Otto considered it a significant achievement that he, as a person with a disability, gained his brother’s guardianship.

Raising Theo and Otto in the late 1940’s and 1950’s, Otto’s mother found herself without educational, home care or emotional supports. To address this issue, his mother created the local Association of Retarded Citizens. She became recognized for her local, state and national advocacy for improved services for persons with intellectual disabilities. This theme of pride and “the passing of the advocacy mantle” ran throughout Otto’s narrative. Otto shared he wanted to write a book about his life and like his mother’s book have it in the Library of Congress. He stated that he felt the constant presence of his mother,

You know what I mean... I was-when I go to meetings once in a while all over the state, all over the country, I was just in Washington a couple of months ago... Giving a talk to doctors...I was the only self-advocacy [sic] there... And I feel like my mama is back of me giving the talk...many, many times.

As Theo’s younger brother and living in a small suburban neighborhood, Otto remembered his teacher’s unfairly low expectation of him, who compared his abilities and potential to that of his more significantly disabled brother. At public school, he attended a small classroom with other children with disabilities. He recalled: “(W)hen I went to school, the kids put us down. ... when we went to high school and grade school we was in just like this room (Otto pointed to the small room where we sat), it was one room only”. In high school, teachers

asked him about his future work goals. “They ask- I wanted to be a cook, they say people like you cannot do it, you know”.

After graduation, Otto worked at “many, many jobs” as he recalled, from operating an elevator, doing laundry, washing dishes, working on cars to sewing mattresses. He became recognized as an advocate after an advocacy agency hired him. As an adult, Otto’s advocacy work took him throughout the United States, speaking with legislators, educators, school children, siblings of children with disabilities and other persons with disabilities. He detailed many experiences which were not only focused on disabilities, but also grief and loss, such as speaking with children in Oklahoma City who had lost family in the terrorist bombing.

Portrait Specific Interpretation – Otto Pearson

Internal validity. Otto’s interview was conducted over two sessions. To verify the validity of the content of the first session, we reviewed the scenes and allowed for additional explanation. Otto maintained a consistency in his memory of the described scenes. For additional immediate verification I often repeated Otto’s statements to ensure the accuracy of the transcription. Otto’s remembered scenes included consistent themes for agency, communion and redemption.

Interpreting the narrative. One could understand Otto’s life through different lenses. Within a historical-cultural context he represented an earlier generation of individuals with intellectual disabilities. He referred to himself and others who had disabilities as “us” or “handicapped” and to those without disabilities as “them” or “you people”, setting up a dichotomy of life experiences. His narrative of his early years, including those involving the care of and institutionalization of his brother, his and his mother’s efforts toward “normalization” within the educational system and the at-large community as well as Jewish community, provided key ingredients in Otto’s identity making process. Equally compelling was that Otto narrated these struggles within a redemption narrative.

Stories from Otto’s late childhood/adolescent years introduced Otto’s life theme of an agentic resistance narrative. Otto shared his significant childhood memory as his bar mitzvah at age 13. The Rabbi declared him as someone/something different from other Jews, “(P)eople like you”. However, with the help of his mother, he claimed his Jewish identity and completed the bar mitzvah.

This assumption of Jewish identity revealed itself in another of Otto's high points. In spite of the Rabbi's declaration of his non-being/invisibility, Otto, in his early twenties, assumed responsibility for Jewish community leadership and became a leader of a Jewish singles' group. In this statewide affiliated organization, he helped organize events to raise funds for a charity. During this adolescent/early adulthood period his identity reflected power/impact and achievement/responsibility.

Otto's recall of an incident with a police officer also highlighted his pervasive theme of agency and the making of a strong group identity. When in his thirties, a police officer questioned Otto about his ability to drive. Otto remembered that the police officer asked: "(W)hat are doing in the back of the wheel. You're not 'posed to drive a car". Otto countered that he had a driver's license and that "I could do it". He added that throughout his life he had many people question him about his driving and "everything else".

When asked what positive came from the police incident (which he identified as a high point) he said: "I could do stuff. ...I prove to all the people. .I could- there's a lot of people say people like us could not do certain things". Not only did he declare this a personal victory but a victory for "people like us."

Another of Otto's high points occurred in his forties. At that time, the agency which his mother help create some years earlier, hired him as its first advocacy employee. In his telling, Otto framed the memory with agentic subthemes of power/impact, achievement/responsibility and status/victory,. These generative actions, represented by his advocacy work, spoke to Otto's sense of responsibility in helping others with disabilities. Of his efforts, Otto declared, "... I helped learn, help talk, I help."

Otto defined the other high points in his life story as those related to advocacy work, such as, maintaining an appointment to the state advocacy and protective services board, the consumer board for the state rehabilitation services commission and the national board of an out-of-state research and training institute. In keeping with themes from his other memories these narrations carried impressive subthemes of power/impact, achievement/ responsibility and status/victory.

Scores: LGS, GBC, SWLS. Otto's scores on the LGS and GBC were slightly higher than the overall sample average. His SWLS score was much lower than the overall sample average; perhaps reflecting his current dissatisfaction with his retirement and new living situation. (See Table 4.1)

Scores: agency/communion. Otto's narrative in terms of agency themes per scene was comparable to the overall sample average; his stories produced 35% fewer communion themes than the overall sample. Otto's narrative contained an almost equal amount of the agency subtheme of achievement and responsibility as that of the overall sample. His stories contained more caring and help subtheme than the overall sample. (See Table 4.1)

Scores: redemption/contamination. The percentage of Otto's redemption scenes in his life story compared equally to the overall total sample average. He had no contamination scenes. (See Table 4.1)

Otto's redemption scenes included his two childhood memories, low point, and two turning points. Otto narrated his earliest memory as the incident when "the teacher told me I can't do nothing and I say to her, 'Yes, we'll make it'". I told her how many people made it and her say, 'you are the only one.'" Otto continued that he did not know what became of the other children in the special education class but that he now "be [sic] somebody". The story scored for redemption as he psychologically grew from this negative experience. He resisted his teacher's prediction and countered "we" would make it and in fact, Otto now considered himself as "somebody". Also noteworthy in this narration was his collective declaration that "we'll make it". This declaration reflected his strong group identity, which was earlier discussed.

A similar internal growth and identity making scene occurred at the time of his bar mitzvah. For a young Jewish male, the bar mitzvah celebrates his coming of age. It is the most meaningful ritual for a Jewish male, signifying his life transition into accepting responsibility for his actions and preparedness to assume leadership within the family and community. Otto, no different than other 13-year-old Jewish boys, expected such for his life. In this sequence we witnessed the collision between collective identities of being a male Jew and being a teenager with an intellectual disability. Otto challenged the religious power structure, defying those that did not accept his identity as an adult male Jew. Otto described this event:

Boys and girls today, today boys and girls, when I went to school there was just boys. [Referring to the bar mitzvah] We had promise that we'd be a man and the rabbi say, "Why are you doing that, people like you don't do that." Interviewer: And what were they saying people like you didn't do? Otto: Be a man in the Jewish lessons. Interviewer: In the Jewish? Otto: Lessons, bar mitzvah. Interviewer: Oh, in the Jewish lessons. Otto: You're supposed to be a man at 13 years old. Interviewer: For the bar mitzvah? Otto:

Yeah. Interviewer: Okay. Otto: You've been to one or two of them? Interviewer: I never have but I've heard about them. So, were you um...? Otto: And people told me I could not do it.... I mean the rabbi tell me, "You are not allowed to do it," and I did it. ...Interviewer: Who, who uh made that happen for you? Otto: My mom did. Interviewer: Your mom. Otto: Mostly I could say in the – today moms make you do everything. Interviewer: Yeah. Do you remember how you felt when you uh went through the bar mitzvah? Otto: Good. Interviewer: Yeah. What did it say about you do you think? Otto: I could do it.

Here, with the help of his mother, he again transformed a negative, life-denying experience into a positive test of his agency, and internally perceived this as a redemptive story.

Otto defined his low point as "when my brother died". He not only experienced grief but a reopening of family wounds, i.e. lack of family support. As he related:

I was there in Cincinnati. You know what I mean, I asked certain people from my family to be here. ...I have got family here in Cincinnati, like I'm dead right now, I'm not, she don't call me, I don't call. Interviewer: Okay. So you have family that you don't uh talk to. Otto: Yes. Like, I am dead. Interviewer: They feel that way? Otto: Yes...but I don't.

Otto assumed the responsibility for the funeral arrangements and "asked people from Columbus that I know who there, big shots" to come and talk about Theo. He explained that this was important to him because he wanted others to know "what Theo did in his life.... Got done, you know what I mean, he has, you know what I mean, he has [accomplished a lot] more than what people thought".

Out of this loss, Otto found a way to memorialize his brother and his accomplishments. For Otto, bringing in "big shots" validated Theo's importance in the fight for rights for persons with disabilities and by extension reflected on Otto's status within the disability community.

The fourth redemption scene centered on his recent retirement, which he named as one of his turning point memories. He recalled that his employer told him, "...that I was going to retire". He asked himself, "What am I going to be doing with myself"? He continued, "I've been laid off and fired from many, many, many companies" but that this was different. The retirement turned out in "some ways good, some ways bad". From this forced retirement he now worked part-time as an advocate at the county board. He continued to struggle with his idle time,

“watching the idiot box [TV] too much”. However, he believed that “I did good” with this unplanned life change.

Otto shared another significant life changing event that occurred when a lawyer, someone he considered a friend, stole money from him. Through his determined efforts, “...I took her to court, I got my money back and I took her license away”. Otto also claimed this scene as his wisdom scene, indicating that he gained wisdom from this negative event. He stated that he felt good being able to stand up for himself and bring justice to the situation, which he described as “...she had took advantage of me”. Although naïve at the time he acknowledged, “I didn’t know better... (chuckles). Now today, yes.”

Vicki Walsh

I interviewed Vicki (Caucasian, age 42) in her work office for approximately 90 minutes. Vicki worked two days/week at the local Down Syndrome Association. Initially shy, Vicki’s interest in the how the digital tape recorder worked and our trial recording seemed to ease her unsureness about the interview. After a few minutes, Vicki enthusiastically responded to the interview questions, frequently talking with confidence about her work. Following the life story questions, Vicki completed two of the written measurements. For the third measurement, the Generative Behavior Checklist, at Vicki’s request, we included Kay (the staff who referred Vicki), who assisted Vicki with remembering her activities and accomplishments in answer to the GBC.

Vicki talked softly but emphasized her points with a slight rise of voice, as punctuation, or laughed when she was amused by her thoughts concerning a question. Her most common affect was confidence and a quiet happiness. The content of much of her interview was of genuine contentment related to her family and work.

Vicki worked as an office assistant and advocate at the Association for eight hours a week. Her advocacy work entailed, for example, talking to school children about her life, attending Association fundraisers or participating as a member of the county department of developmental disabilities Leadership Advocacy Network. Vicki stated that she liked the work at the Association because it “makes me feel good inside...it makes me feel important... . Because...um...everybody thinks I can do it. I can do, a lot of stuff..., and um, it makes me proud of myself ”.

Vicki also worked as a housekeeper two mornings a week at her neighborhood YMCA.

She smiled and spoke proudly that she “got a proposition (sic) to work at the front desk” at the Y. Social Security Disability benefits supplemented her work income.

Vicki’s religious beliefs and activities also provided satisfaction in her life. She earnestly stated, “I believe in God!” She lived her faith by worshiping weekly at her parish church and celebrated Catholic holidays with her family. When asked what made being Catholic important for her, Vicki answered, “(I)mportant. Uh, to let God know that I am, to let God know that I am, um. (pause) Oh, come on, to it, yeah, I, to think about Him”.

Catholicism also influenced Vicki’s education as she attended a Catholic elementary Montessori school. She later attended special education classes (except for home economics) and graduated from the local high school. Overall, Vicki did not talk about her school in relationship to important memories, rather she volunteered the above information when answering the demographic information. In narrating her story, she focused on her childhood and adolescent memories involving friendships in the neighborhood and positive reading and writing experiences which occurred outside of school.

Referring to her adult relationships, Vicki identified Kay, the Association staff member, as an important positive influence because Kay encouraged Vicki’s independence. From Kay she felt that “I can do stuff”. The value of friendship remained strong throughout her interview. She stated that, “I want to keep my friends” and that one way to do this was “to respect my friends to keep my friends- I believe that everybody, treat everybody with respect”. In addition to her active participation in advocacy events, Vicki participated in group activities, such as a writing group with other women with intellectual disabilities. This effort produced a book titled, *Writing for our Lives*. She stated that the experience made her “feel confident about myself and proud,...that I’m popular”. Vicki enjoyed the experience of *Writing for our Lives*, in part, because “all my friends are part of it, I’m part of it”.

Family relationships also figured meaningfully in her past and current life. Vicki, the youngest of four, fondly remembered times with her siblings and noted that her life changed at 17 when her 37-year-old brother died of cancer. She understood then that “God loves me, I miss him”. In her adult years, she continued this strong family bond and as she grew up “I could talk to my parents about anything”. Her happiest scene was “just talking” with her parents, with whom she lived.

Portrait Specific Interpretation- Vicki Walsh

Internal validity. Initially Vicki appeared somewhat confused when considering her life as a movie. However, drawing upon her experience with and knowledge about writing and film making, she understood terms, such as, characters, description, or describe. While at first she did not provide much detail to her answers or replied with “I don’t know”; within the period of talking about a particular scene or memory she added details, filling out the picture such as the name of the area in which she lived, how many siblings she had, or how her brother died. Vicki asked for clarification for conceptual words, such as, wisdom. Once explained, she provided an appropriate scene showing wisdom. Vicki was clear in what she said and what she remembered.

Vicki’s narrative contained a story coherence, which integrated her personal beliefs and values with her experiences. As a storyteller, Vicki made the themes of her life clear.

Interpreting the narrative. Overall Vicki described her life story with words evoking happiness, companionship, and self- pride. As a child, she remembered intimate family and neighborhood memories, as a teenager, she remembered dancing, reading, and writing. As an adult, she was enthusiastic about her achievements and generativity, such as speaking to schools, writing books, and working for the good of others.

Although she did not conceptualize her values as extending beyond her immediate circle, she produced a narrative that said ‘I want to tell others all about me’ thus putting a human face on the label of Down syndrome. In this sense she created a generative story of one individual sharing the larger story of humanity. That Vicki’s communion score, specifically, the unity and togetherness subtheme, was higher than the sample average attested to this sense of being part of a larger group experience.

As an adult Vicki felt good about her multiple selves or identities; family member, child, friend, worker, advocate, writer, and a person with Down syndrome. Vicki remembered the parent and child discussion regarding her diagnosis of Down syndrome that occurred at age 12. This late childhood/early adolescent period is a critical time for ego development “in the direction of conformity and celebrates the sameness with other selves...”. (McAdams, 2009a, p. 376)). For Vicki, at age 12, her identity incorporated the sameness of others with Down syndrome. One could consider this parental/child discussion as a key moment in her group disability identity making and – importantly Vicki narrated this memory as a redemption scene. Subsequently, Vicki’s group identity was positively nurtured through group activities, such as

participating in a writing group for women with intellectual disabilities and becoming an advocate for persons with disabilities.

In understanding Vicki's identity making process, one appreciates that her early years focused on her positive attachments to those closest to her, beginning with her parents, expanding to her siblings and then to the neighborhood, school, and parish. She developed a positive self-image as a young girl. The identity making process continued into preteen and young adult years evidenced by the acknowledgement of her diagnosis and the resultant academic and problem solving challenges. Vicki described those challenges of "Down syndrome" as "...I think things slowly, in some cases...if I don't understand anything at all that I let, um, people know".

Recognition of those differences led to specialized educational services and chosen segregated social opportunities, such as the writing group. Rather than discrediting her positive self-identity Vicki developed a positive group identity as a person with an intellectual disability. Equally meaningful her social identity continued to develop with internalization of the positive messages from her friends with disabilities, disability agency staff, and her family. The success of these chosen opportunities resulted in Vicki's positive identity today as an adult who contributed to society-at-large, while recognizing her valued role as an advocate for persons with disabilities. She articulated this identity making process in her adulthood when she offered a memory about receiving elementary students' thank you notes, which "made me feel proud about myself, that they like me".

Looking toward the future Vicki wished to live on her own one day. To accomplish this she participated in independent living skills training. Confirming her positive self-identity Vicki ended the interview with "I turned out great".

Scores: LGS, GBC, SWLS. Vicki scored 40 on the LGS, and 40 on the GBC. She scored a 4.6 on the SWLS. Her LGS score was slightly lower than the sample average, her GBC score was slightly higher than the sample average and her SWLS score was slightly higher than the sample average. (See Table 4.1)

Scores: agency/communion. Vicki's scenes included .91 agency themes per scene, and 1.45 communion themes per scene. Vicki's most frequently narrated agency subtheme was achievement and responsibility (57%) and her most frequently narrated communion subtheme was unity and togetherness (40%). Vicki's agency score was comparable to the overall sample's

score; her communion score was considerably higher than the overall sample. (See Table 4.1) Vicki narrated her scenes with almost double the frequency of unity and togetherness than the overall sample. Her numerical scores for communion and agency provided confirmation regarding the qualitative finding of her strong sense of communion witnessed by her stories of friends and family and agency evident in her work related stories.

Scores: redemption/contamination. Vicki's percentage of redemption was slightly lower than the total sample average. (See Table. 4.1) From a total of 10 scenes, Vicki narrated two redemption scenes and no contamination scenes. Vicki told her low point scene from a redemptive perspective. She remembered at age twelve that her parents talked with her for the first time about her diagnosis of Down syndrome. The emotional content of this story moved from her feeling that it was "kinda scary" and crying to feeling happy because her mother's comforting words, "my mom told me that I'm special, and that made me happy". This feeling of specialness restored her overall psychological state of feeling happy and positive about life in general.

Vicki narrated her second redemption scene as occurring at the time of her brother's death. She also described this as her turning point scene. Referring to her brother's death, she simply stated, "I did not like that". From this loss she understood and grew in the belief that "God loves me".

Lower Generativity Group

Andy Baker

I met with Andy, (Caucasian, age 43), two evenings in his apartment. Andy's apartment was one of 40+ apartments in a building managed by a non-profit agency serving persons with disabilities. Andy stated that he did not require such assistance but appreciated that he could all upon staff if needed. Andy shared his life story with an openness and introspection of someone who thrived on processing his experiences.

Andy often used pejoratives to describe himself, such as "weird". At times, his stories centered on sadness, self-doubt or fear, for example, "And her family didn't want anything to do with me because her step-mother was, uhm, so afraid that I was going to bring bedbugs into their house." In one scene, he recalled that (P)robably that I was happy but kind of scared, kind of nervous and kind of a bit insecure all at once because it was a new experience and all". Overall,

Andy's emotional content could be described as self-doubting and melancholy. His answers reflected a seriousness and at times, uncertainty .

Andy had worked twenty hours per week for twenty years as a clerical assistant for the city. He exhibited flexibility at his work, for example, with technological changes, "I've worked for the city a long time and I've noticed how technology advances in a different way.... I find that kind of interesting." In addition to salary, Andy received SSDI based on his intellectual disability.

He described himself as a Roman Catholic who regularly attended his parish church. He attended to avoid bad luck, and to make his parents happy. "I think I always feel I'll have good luck if I go to church because that's what my parents want me to do."

Andy's public school education included placement in a self-contained class (grades 1-6) and individual tutoring in junior and senior high school. During the interview, Andy did not focus on his educational years but rather on his current adult life and intimate relationship issues. He shared that after his junior year aptitude testing his teacher recommended a trade school; telling him that he was not "college material".

Andy received no formal case management assistance. Other than infrequent activity with a social group supporting persons with disabilities, he had remained outside the formalized adult disability system.

His life story spoke of parental and sibling concerns for his competency to handle financial and practical matters. Andy struggled with a long-term relationship with a younger woman, with whom he felt connected due to her challenges with bipolar illness and the sense of not quite fitting in. However, these same issues posed an emotional challenge for him to maintain an intimate, equal relationship.

Andy felt a close bond with friends and shared the commonality of disability. He called himself a romantic and "I kind of connect myself with people, especially women, who feel lonely and alienated..." Again in his words,

If you're disabled or not disabled nobody wants to be alone.... It doesn't matter what the disability is. You're going to connect to this person if you feel and think the same way.

Andy's sense of self was caught in a web of comparing his intellectual and educational status with other family members. His college educated parents and sibling worked in the

educational field. He highlighted this tension in his narrative regarding his relationship with his father:

If we didn't have activities, if we didn't have something we could do together, we seemed to be kind of distanced and we wouldn't be talking as much. Be if we had an activity that we'd do together then we seemed to be good friends.

Andy also tried to connect with his father through his fidelity to the Catholic faith. "So, it's like, I kind of feel like I'm doing the right thing because of my upbringing".

While he considered himself happy, he identified as the 'underdog' in life. Andy found him attracted to those who needed a friend. He metaphorically called his life quest, the "Find A Way Zone" [named after the apartment complex]. Andy's cognitive disabilities were a result of spinal meningitis at the age of three; a significant developmental period where the child attempts psychological autonomy from his caregivers (Erikson, 1963)

Portrait Specific Interpretation – Andy Baker

Internal validity. Andy's telling of his life story, from his earliest memory to his anticipated future, followed a recognizable and predicible path. His story possessed predictability and coherency, bringing the listener down a well-cut path of experiences, values and beliefs.

Interpreting the narrative. Andy's story revealed elements of emotional tension generated by his ambiguous role in his family and resultant expectations. With his parents as guardians, and the younger sister as future guardian, Andy could not establish an identity as adult son or older brother. He desired a more typical adult child and sibling relationship. The high value that the family placed on education served as another barrier to Andy's psychological place in the family. Andy's life story contained strong elements of disability related identity markers, as evidenced in his narrative. In many ways he remained psychologically tethered to his parents, which produced a dialectical tension between his identity as independent adult and eternal child.

Andy balanced an identity consisting of agency and communion and it is from this base that he constructed his meaning. Not without a struggle, he successfully established his independence and found companionship.

Scores: LGS, GBC, SWLS. Andy's scores on the two quantitative measures, LGS and GBC were considerably lower than the sample's average scores. His SWLS matched closely with the sample's average score. (See Table 4.1)

Scores: agency/communion. Regarding scoring on the qualitative life story narrative, Andy narrated more agency themes per scene and less communion themes than the overall sample. Andy's two most frequent subthemes, agency achievement and responsibility and communion love and friendship occurred more often than in the overall sample. (See Table 4.1)

Scores: redemption/contamination. Andy's one redemption story was of interpersonal personal growth and fulfillment. This scene, also his turning point scene, was congruent with his overall theme of transcending loneliness and feelings of being an outsider. Equally so, his contamination scene, which was also his important childhood scene, spoke to this pattern of claiming an outsider identity. (See Table 4.1)

Ed Frazier

Ed (Caucasian, age 65) lived alone in a poorly maintained multi-unit apartment building in an urban setting. He worked part-time at a family owned deli near his apartment. I interviewed Ed twice, a few weeks apart.

Our two interviews lasted a total of approximately three hours. Ed loved to tell stories in a style of a rural raconteur. His stories traveled many bends and circles and oftentimes after these colorful verbal trips I would direct him back to the question.

Ed proudly showed me his small apartment filled with photographs and mementoes from his trips to Nashville and other places as well as Elvis and sports memorabilia. Ed's family Bible, surrounded by plastic crosses and red flowers, prominently set on his front room table. Often, Ed gazed toward a specific family photograph and invoked a promise that he would be "up there in Heaven" with his family someday.

The emotional content of Ed's story contained a great deal of worry and pervasive distrust of the world. He worried that "(P)eople wasn't to borrow money off of me. People steal money off of me." And that he not let anyone in his apartment. He worried that "(M)others and fathers don't take care about the kids and stuff nowadays."

In matters focused on his family and friends and his personal achievements, he exuded an affect of happiness, security and pride. For example, he shared that (M)y grave is already paid for. And my coffin is already on the tombstone (sic). He was to be buried "couple rows down from her (his mother)". Elsewhere he stated that "Everything was real good as I was growing up."

At Ed's request, I stopped by his workplace, where he had worked for several years. He introduced me to the other employees as "she's talking to me about my life" and invited me to see his kitchen workstation. The employees and owner were extremely complimentary about Ed's work and his 'place in the deli family.' The deli owner frequently invited Ed to his vacation lake house. Ed also received Social Security Disability income as a result of his moderate intellectual disability. [Ed asked that I look at his 'official records' that described his disability as moderately impaired.]

Although he did not currently attend a church, Ed professed a strong fundamental Christian faith of right and wrong; Heaven and hell. God talked to him, and he claimed himself as Jesus' angel. Ed's deceased family also served as a source of strength for him.

For Ed, God was scary at times and he passively waited for God to take him to Heaven. In Ed's world angels inhabited the earth. When probed about how his religion fit in his life, he replied, "I feel good you know. But you have to be careful who you hang around with, who your friends are. ... You have to be careful". God protected Ed and told him whom to trust. "He say be- you got to be careful who you trust, who your next door neighbor-next door neighbor are, who your friends, who you can trust. ... Yeah, he guides us."

Ed's life story possessed a keen sense of rejection from the educational system. He remembered being passed from class to class without learning to read or write, until "they didn't want me there...and they kicked me out of school there because I did not know how to read. So I went to (school name)," [a segregated school for children with intellectual disabilities]. In his narration one heard the sadness of this loss of a neighborhood school and the isolation from his beloved peers. This separation placed him outside of the neighborhood circle, making him different and denying him a communal experience of neighborhood socialization.

Family and community figured prominently in Ed's life story and identity making process. Ed lost his mother ten years ago and his sister within the past year, he saw his other sibling sporadically. He secured his own apartment four years ago, after he lived many years with his mother and maternal grandmother.

Ed sporadically attended senior programming at two agencies; one directed toward adults with disabilities and the other directed toward seniors. The non-disabled program also offered him medical services, including home health services related to his diabetes, shopping assistance, and financial payee services. Ed considered this agency's activities "too boring" but took pride in

recounting his annual holiday role as Santa Claus. He claimed this identity by owning his Santa suit, ensuring an on-going role and place in the community. More frequently, Ed attended the program centering on individuals with disabilities, participating in community oriented volunteer work.

Ed declared the theme of his life movie as, “How I was growing up in this world”. He shared that he had polio as a child and that a doctor said that he would never walk; to which Ed recalled “...I told him he was wrong. I was a dancer at one time”.

Much of Ed’s life story centered not on his disability but rather his love for his family and friends. He considered himself an equal, a fellow country music lover, traveler, and Christian man. His world was not one of disability but of meeting and connecting with country music musicians. Ed’s many pictures of himself with recording artists and their autographs, signified to Ed that “they know who I am”.

Ed’s narrative carried a strong theme of distrust and the belief that “the old days were better”. Through these memories he created a personal mythology of a communion rich past qualitatively better than the present. He recalled black and white children playing together. “It was a good life. We just walk home, holding hands. But now the good old days is gone. And it’s bad.”

Ed processed life in concrete terms, with little shade of ambiguity. He viewed life as tenuous and fragile, “(Y)ou might be here now, you might be gone tomorrow.” His strong values and beliefs reflected opinions found on many conservative talk radio shows. Regardless of the opinion, Ed exhibited a passion about today’s political and cultural events. He took pride in being part of the community and desired to help others.

Portrait Specific Interpretation- Ed Frazier

Internal validity. Two issues, posed challenges for Ed; his difficulty with understanding concepts, such as wisdom, and the use of the movie and scene analogy. After I eliminated the movie analogy, the interview flowed more easily and Ed freely talked about his life. Understanding his articulation also proved challenging for the transcriber and me. Despite that I prepared list of potentially difficult phrases and words for the transcriber many errors needed correction.

The content of Ed’s life was overwhelmingly consistent throughout the interview. He narrated with a communion theme throughout his life story, whether in his actions or belief

system. The occasional discrepancies of dates or sequences did not contaminate the overall life themes or emotional content.

Interpreting the narrative. Ed's work provided him with a sense of agency as well as communion. Throughout his life he had claimed an identity of resistance.

Scores: LGS, GBC, SWLS. Ed scored lower on the LGS, GBC and SWLS than scores of the overall sample. (See Table 4.1)

Scores: agency/communion. The numerical scoring of Ed's agency and communion themes confirmed the overall sense of Ed's narrative. His agency theme per scenes were less than half that of the overall sample. However, his communion themes per scene matched those of the overall sample. Ed's story contained more unity and togetherness than the overall sample. (See Table 4.1)

Ed's positive scores for status and victory occurred most often in his childhood, such as when he was chosen as batboy for the local major league baseball team. Ed's positive scores for unity and togetherness similarly came from his narration of being part of a community that "everybody knew who you was". A strong sense of unity and togetherness infused Ed's early childhood memories.

Scores: redemption/contamination. Ed's two redemption stories occurred at the time of his sister's death and in his childhood. Following his sister's death he comforted himself with a belief that he would see his family in Heaven. (See Table 4.1)

It hurts me a little bit. But she told me, 'Ed, walk on with your life now. I'm back home now in Heaven. I will see you again in paradise. And I will meet you at the Golden gates of Heaven.' She will be there. All three of my family will.

The second redemption scene involved a series of unplanned family moves throughout the city due to urban renewal. After a first disappointing move and receipt of compensation from losing their home, they eventually relocated to a part of the city that reconnected them to friends and job opportunities. Ed related:

And this guy own the grocery store, called Mr. Lucas, he owned a grocery store on Eastern Ave., his grandfather used to own a grocery store....So I helped his father out. ... So I go, oh my God, Mr. Lucas. Wow! He said, 'Ed, how you been?' I say, Ok. And he goes; 'you want to work for me?' I said Sure. What to do? 'To stock the shelves and help me slice the lunch meat and do the cash register.' I did all that.

Ed credited his current happiness as a result of this move; he stated that he was: in love with the neighborhood. ...I have the New York Deli Café here. They love me over there, I love them. You know, we have ups and downs, you know? But, you know? But I'm doing real good.

Kevin Little

I met with Kevin, (African-American, age 44) at the county developmental disabilities office, close to his apartment. He lived alone in an older federally subsidized high rise in an urban neighborhood.

Kevin was an engaging and polite man who talked extremely fast while maintaining constant eye contact during the approximately ninety minute interview. He smiled frequently, held the door for me and called me, "ma'am" throughout the interview. He appeared invested in assuring me that he was a "good person". As I gathered from the interview, he meant that he had no arrest record nor used alcohol or drugs. During the interview he frequently told me to check with his service facilitator; that he was telling the truth. I reassured Kevin that I believed him and wanted to hear his life story from him.

Kevin's rapid speech and overall fidgetiness revealed a high level of anxiety. The questions did not evoke the anxiety but rather the possibility that I would not believe him and would view him in a negative light, i.e. not see him as a "good person".

Kevin recently started his first job as a part-time dishwasher at a small family owned restaurant/bar. He also volunteered part-time for the past two years as a dishwasher for a Meals on Wheels program. The county agency paid Kevin \$10 per day for his volunteer work and with this money he bought items that he could not afford on his work or SSI income, such as a computer or DVDs. Kevin shared that he had two long-term career goals, to become a bellman and, as a result of taking a community photography class, to become a professional photographer.

Kevin's narrative did not include significant spiritual or religious content. When asked if a religious or spiritual belief or experience kept him going he responded: "well to tell you, you gotta keep yourself going sometime ...you just got have faith in yourself...". Kevin's grandmother (now deceased) provided him a source of comfort and inspiration, as he stated, "(Y)ou know, that why I do this now, I'm with her all the time, you know".

Kevin first attended his neighborhood school for special education classes and later transferred to “job adjustment, it was a slow learner job adjustment” where he graduated. In Kevin’s story his school success at times took second seat to his responsibility for caring for his grandmother, who had cancer. He recalled that “I was the favorite student in the whole school. Like everybody, teachers liked me in the whole school down there”. For Kevin the teachers liked him because of “how I carried myself. ... You know, I wasn’t no trouble maker...I had to take care of my grandmother at the time and it set you back, you know”.

Reference to Kevin’s parents was strikingly absent from his life story. He did however mark his life through his relationship with his grandmother and regarded his move to his grandmother’s home as saving him from living on the streets. “Because I had to take care of my grandmother...had to step away from them”. While Kevin found commonality in his degree of family poverty with his ‘street’ peers, he considered himself different in the most important way- he followed the law and did not use drugs.

In addition to his grandmother’s powerful influence, Kevin credited several persons who came into his life via the educational, or social services system as positive influences. Referring to one individual he remembered: “If it wasn’t for Sally, man, ...it felt good when I was around her, she made me feel comfortable and I applaud that and then like what they was doing for me...”

Portrait Specific Interpretation- Kevin Little

Internal validity. Kevin presented a coherent and consistent life story with central themes that were present in key memories. His story possessed predictability once the reader understood his life themes. Additionally Kevin’s case manager confirmed details in Kevin’s life story as well as confirmed an overall theme of successful survival. Lastly Kevin appeared to comprehend both the narrative questions and questions from the quantitative instruments.

Interpreting the narrative. Kevin’s measured his own success compared to that of his social environment.

He prided himself on “not running the streets”, not taking drugs or drinking, and staying out of legal trouble. He also compared his value system and resultant behaviors to other African-Americans, which he referred to as “project blacks” or those trying “to be stronger than the law”. As illustration, he framed his happiest scene as “never been in trouble with the law, being nice to

people, showing respect and people who have been nice to me”. Kevin’s identity contained the element of comparison with those who “show respect and are nice” to those who don’t.

He also internalized a resiliency in a hostile environment. He identified his life theme as *Survival* and would name his life story movie *Experiences*. In his narrative, Kevin perceived himself as a good person who fought the constant demons of peer pressure and racial discrimination. In this movie, Kevin believed that the audience would see the ‘real Kevin’ as “he had it tough but he survived”. Amidst this turmoil, he possessed a strong sense of gratitude for people who have helped him along the way. His story included a rich history of surrounding himself with positive people and possessed the resiliency to elicit and accept help from others. He believed that “when you’re around good people, you know, you know, make you feel good.”

Kevin’s identity can be understood as a coming of age story about young African-American man in an urban city. As a theme for his movie, he wanted others to remember that “he had it tough but he survived”.

Similar to other interviewees, Kevin fell into the “invisible minority” of individuals who appeared without disability but lacked the ability to independently problem solve in layered situations or to make well-thought out decisions. Peer pressure is difficult to resist and his grandmother, as well as those who later come into his life, provide that compass for resistance. His attachment to his grandmother grounded and shaped his identity. In this excerpt he explained:

that’s why I never been in trouble because – I’ve almost been there but I had to take care of my grandmother too and I had the experience with that, you know. Well, like I would say, a lot of blacks well I am poor myself like them, but they got their personality that’s how I was raised and they wasn’t and I’m trying to – at one point I had to step away from them because I had to take care of my grandmother

He focused on the positive and the future, he tried to “get the bad times farther away, try the good times”. His ability to find the redemptive quality of a situation revealed itself when he described caring for his dying grandmother. He reframed this difficult and sad situation as a life saving escape from the pull of the streets and his peers. Now without his grandmother, Kevin maintains the belief that you keep trying, “(T)hat’s only option, you know, cause if you don’t try to better it then don’t complain about it, you know, it’s not going to help yourself to complain about it”.

The variable of race presented itself more frequently in Kevin's identity making process than the variable of disability. Kevin personally felt racial discrimination beginning in his early adult years. As he remembered, "...see when I was in the job adjustment class that time I remember I didn't know about racism". When he moved to a racially diverse, urban neighborhood, he became aware of "seeing 'em cross over" [white people crossing the street]. About four years ago, Kevin began helping a neighbor,

white guy, Greg...He was uh-he had cancer and um I stood by him, you know,... I would go to the store for... I would do things for him man. His girlfriend she didn't like me at all and I couldn't understand why.... I just can't understand why we stereotype... I mean because I never been in trouble in my life, you know. I don't gang bang

A second incident occurred when Kevin lived in a "church house" and a nun accused him of stealing; to which Kevin took great offense. He remembered that another staff explained that: like she got a whiteness in her, whatcha mean, whiteness you know. And I can't say she go to church why she don't trust me, why she don't trust me. I live here. I mean y'all trust me, you know what I mean, why she don't trust me, what I am goin' do to her and that really – that really bothered me too. That really bothered me and um that's what I'm talking about stuff like that, you know.

These encounters greatly bothered Kevin who valued that others saw him as an individual and as "good person"; not for the color of his skin.

Scores: LGS, GBC, SWLS. Kevin's scores on the LGS, GBC, and SWLS placed him in the lower end of the overall sample scores. He scored 50% less on GBC than the overall sample average. (See Table 4.1)

Scores: agency/communion. Kevin's scenes contained a lower percentage of agency themes per scene than the sample but a higher percentage of communion themes per scene. (See Table 4.1) His high scores on the agency subtheme of achievement and responsibility and communion subtheme of caring and help confirmed the qualitative interpretation of his narrative. (See Table 4.1)

Scores: redemption/contamination. Kevin's life story produced three redemption stories (slightly higher than the overall sample) and no contamination stories. (See Table 4.1) Kevin scored an additional point for enhanced agency in his adolescent memory. All of his redemption scenes were narrated with psychological growth content. In each scene, Kevin

actively reframed his perception of a negative environment or circumstance or changed his behavior to produce a positive situation from a negative event.

This self-reflection and change appeared during his lowest point scene, his grandmother's illness and resultant death. Although he grieved for his grandmother, he took pride in caring for her. He possessed the self- insight that his age peers would rather run the streets than take care of their grandmothers. In his words, "They'll run the streets, they'll run the streets and all the grandmas everyday, you know, they won't care." His family reinforced his personal identity, telling him that they were proud of him. The scene also scored for unity and togetherness and caring and help. This scene provided a meaningful identity making moment, i.e. the internalization that he was important to loved ones and contributed to something larger than himself.

Kevin's turning point scene also read as a redemption scene. In this narrative Kevin described that he bounced from place to place after his grandmother's death and found himself in negative situations. A physical move from this environment and becoming involved with a priest that connected him to others who helped him, positively changed the course of his life. In this scene Kevin actively changed his life, rather than passively waiting for life to change.

The third redemption scene also occurred during Kevin's early twenties. Again, this adolescent memory revolved around his grandmother's illness and death. At this grandmother's hospital bedside, he felt anger with his family (who had not helped him care for his grandmother), when they accused him of smoking crack. He recounted that his responsible character and actions outshone the accusations. Kevin felt vindicated and understood when one family member spoke up for him. He reframed this negative accusation into an opportunity for his family to hear "the truth" about his loving character and devoted actions. Also compelling in Kevin's retelling was his fear of being left alone and vulnerable to his peers and hard economic circumstances. As he remembered, "(V)ery scared. Cause I didn't know where I was going be living at, cause I was I was almost homeless too...". His self- awareness evident in this scene matched his overarching redemptive pattern of continued survival amidst physical and psychological obstacles. Kevin reframed these negative experiences into opportunities for growth and solidified his belief that "there's hope". He continued,

hope, hope, hope. Not luck, hope...because I could have been doing things I had no business like the- a lot of people I knew they were, might be getting locked, they have

records and...that's what my grandmother was scared of. That she scared her so. That she was proud of, cause I didn't get in.

Teri Uhl

Teri (Caucasian, age 35) and I met twice, once in her home and once at the Down Syndrome Association office. She initially wanted to meet in a park near her home. After we discussed the disadvantages of meeting in the park, such as, noise and extreme heat conditions, Teri offered to meet at her home, if her staff would not stay in the same room. From this initial interaction, I gleaned that Teri considered herself an outsider and that she felt a need to protect herself.

Teri provided me with precise directions to her middle class suburban home. We met in the dining room, while her housemate and staff sat on the back deck. The two-bedroom condominium suggested the personalities of the housemates. Printed charts on the refrigerator designated responsibilities and emergency contact numbers and provided the only hint of agency involvement.

Both times that I met Teri she dressed in a skater style, a slightly younger style than her age suggested, graphic tees, camouflage shorts with a wide leather brown belt and bright yellow tennis shoes. Only her facial features characteristic of Mosaic Down syndrome distinguished her from the typical young adult.

Teri had a great interest in the life story interview. She was deliberate in her answers and asked me to repeat questions that she did not initially understand. The extended pauses during the interview related to her genuine thoughtfulness in answering the questions. She shared her life narrative with great story telling ability, replete with details and an authentic sense of remembering/constructing her narrative as she told the story. One instance of this eloquence occurred when she recounted the shock and puzzlement of a young child watching the destruction of the family because of her father's alcoholism.

Aware of her need to talk slowly and clearly, Teri paced her words, a result perhaps of many years of speech therapy and her recognition of the difficulty that others (strangers) had in understanding her. She frequently laughed at herself when she talked about her failings or described herself, such as, calling herself a 'boomerang kid' for the all the times that she returned home and bounced back. Throughout the interview Teri displayed this sense of humor.

Teri's voice inflections when answering questions related to her feelings and certain events, such as carrying the Olympic Torch or her father's hospitalization, provided evidence of her ability to assign strong emotional content to her life story. However, at times she revealed her story with emotional tacitness and guardedly presented the actual details of her current life. This reluctance to share details seemed to match the Alcoholics Anonymous code of confidentiality in which she participated.

At the time of the interview, Teri did not work, but rather volunteered for the Down syndrome Association (DSA). She served on the board of the local DSA and frequently spoke at schools and community meetings for them. Additionally, she recently enrolled in college, taking presocial work courses. When asked how she spent her week, when not in class, she offered the vague comment, "I go to appointments". Teri stated that she "worked years ago" at a sheltered workshop. She received Social Security Disability benefits due to her intellectual disability.

Teri identified herself as a devout Presbyterian, although she did not regularly attend church. As she confirmed, "I believe the Lord Jesus Christ as my Savior, that He died for me, and rose again, for my sins. I believe that I am saved". Both parents were retired Presbyterian ministers. Teri stated that the family relocated many years to this area due to her mother's transfer.

For Teri, faith played an important part of her daily life; she acknowledged that her life was "(b)ack on track through the Lord". Teri believed that she had a purpose to do good, although not knowing exactly what that purpose was, "he put me here for reason, um, what the reason is, I don't know".

She attended special and non-special education classes throughout her school career and graduated with her class at age 19. Teri was the younger of two children; her father (age 80+) died last year. As Teri told her life story, she talked with ambiguity when speaking about her mother's support for her. Teri's small but significant support group provided a lifeline for her sobriety and spirituality. "The way I am today, it's because of (sponsor's name) and the Lord." She spoke caringly about church members who provided spiritual support and guidance to her. Her life story read as a narrative on the impact of alcoholism on her and her family. Many of her scenes reflected back to her own battle with alcoholism and its repercussions, her family's struggle with her father's alcoholism, or the redemptive quality of believing that God had a purpose for her.

Portrait Specific Interpretation – Teri Uhl

Internal validity. Teri's narrative possesses a thematic coherence. Her overall story linked together her episodic memory and future goals to define her adult life within the social context. From the earliest memory, which was created from her parents' reconstruction of Teri's diagnosis of Down syndrome to the creation of her 'second/future movie of her life story', Teri's life theme firmly held purpose and unity. Her personal struggles and negative roles had moved into an ongoing redemptive story of helping others and realizing her own human potential.

Interpreting the narrative. Teri's developing identity as a young adult bore witness to her strong moral/spiritual connection, her personal identity as an outsider or rebel, her individuation from an alcoholic family, adolescent role confusion, and current struggle with alcoholism. Her parent/child and peer struggles in adolescence marked a confusing time of where 'do I fit'.

Teri's remembered past focused on her destructive attempts to fit into a nondisabled peer group who drank and used drugs. "I was rebelling against myself- I didn't want to be different and I was told that I was different [from my family and friends] by mother." She vividly recalled her mother's chastisements not to associate with nondisabled peers, because she was not like them. Her mother continually made her feel different, less important than others in her world. Teri struggled with drug use and alcoholism since her teenage years and continued to battle this addiction.

Her connection with Alcoholics Anonymous provided her an emotional and spiritual home. In her personal struggle she found the common struggle of all alcoholics. Her language, which reflected the AA vocabulary, testified to her inculcation of AA's philosophy.

A qualitative analysis of Teri's story also revealed the identity making process of a young woman with Down syndrome. Through her work with the DSA she felt important, worthwhile and generative. She belonged to a larger "we" when she talked about herself.

As a young woman, Teri personified Erikson's question of adolescence - Who am I and How do I fit in the adult world? Her parents' deep depression, as a result of receiving the diagnosis of Down syndrome, provided Teri, at age two months, with her underlining narrative - of someone in need of constant care and/or institutionalization. Within this narrative was wrapped her father's alcoholism and her mother's pervasive message to Teri that she was not like "normal people".

Rather than a story of contamination, Teri psychologically repositioned it as a redemptive story. She identified herself as someone who not only persevered but was strongly agentic. She believed that she had God's power to make a positive difference for herself and others. Her actions, such as, serving as board member for the Down syndrome, and carrying the Olympic torch in 1996, testified to her generative and agentic identity. Her narrative was to "prove the doctor wrong". And with the support of her friends she felt "like I can conquer the world now".

Perhaps because of her "other" status, i.e. as one whom needs constant care, institutionalization or protection she placed great value on recognition on her achievements, as those mentioned above. She identified herself by interchangeably using the words important and worthwhile.

Her journey was one of movement, of constant growth but not without setbacks. She described herself as the "boomerang kid" and the "prodigal son", when she referenced her independent living and movement toward individuation.

Scores: LGS, GBC, SWLS. Overall, Teri scored lower than the overall sample on all quantitative instruments. She scored slightly lower on the LGS than the overall sample, 50% lower on the GBC than the overall sample and 20% less on the SWLS. (See Table 4.1)

Scores: agency/communion. Teri's scores for agency and communion themes per scene matched the overall sample. Her most frequent agency subtheme, achievement and responsibility also matched the overall sample. However, Teri's communion narratives contained more than twice the dialogue subtheme than the overall sample, she also scored slightly higher on the caring/help subtheme. (See Table 4.1)

Scores: redemption/contamination. Fifty percent of Teri's scenes contained redemption themes. No scenes contained contamination. (See Table 4.1) The four scenes containing redemption included, her low point scene, turning point scene, childhood scene, and adult scene. Teri's turning point scene scored an additional point for enhanced communion. Content themes for the four scenes included one improvement theme and three recovery themes.

Teri narrated her low point scene as occurring at the time of her parent's resultant deep depression following the diagnosis of Down syndrome. Teri recognized that in this sequence, "(T)here was a good part and a bad part." The "bad part" contained the depression experienced by her parents when doctors diagnosed two-month-old Teri with Down syndrome. In Teri's narrative she related that one doctor told the parents, "to do what you can with this child...on the

other hand, the pediatrician... told my mother ‘You can take her home and love her, but she’ll never do anything...She’ll never read or write. Or talk well.’ Her memory was unclear whether her mother actually said the following or if she just thought it, but her mother heroically stood up to the doctor and said, “Lady, you take care of her physically. But I will take care of her mind.”

This story moved from condemnation of a baby’s future to a mother’s redemptive spirit of protecting and caring for her child. In this same narrative Teri acknowledged that her parents experienced a depression, following this diagnosis. Her parents visualized the many images of children with Down syndrome wasting in institutions. Teri also credited the late diagnosis and lack of emotional preparation to their depression. “So-, and when it was discovered that I was Down syndrome, um, both of my parents were in deep depression.”

The mythology that surrounded Teri’s beginnings contained what McAdams (1993) described as a mythology replete with images of hero (mother), villain (doctor) and victim/child (Teri). Teri’s victim or child imago proved her cross to bear, as her life story bore witness to the tension between her mother, her internal conflict between and identity as a ‘disabled child’ and an identity as a ‘typical’ adolescent and her struggle with alcoholism which infused her adult identity.

In her life story, Teri addressed this internal conflict to find a sense of agentic self against the prognosis of eternal child. She found redemption, if not revenge, in her intellectual successes [this is Teri’s self-described ‘good part’]. “Because I can prove to that doctor, um, say, look at me now. Because I’ll tell you something that you don’t know...I’ve gone to [name of college] I’m taking up pre-social work.” When asked how she felt about this she laughed answering, “Shoot, I feel kind of good”.

The movement in this low point scene flowed from negativity [her parents’ depression] to her mother’s assertive stance against the doctor who condemned infant Teri to a life of eternal childhood and in need of protection. Even now, Teri also took pleasure in disproving the predictions with her enrollment in college. The content of this scene illustrates Teri’s psychological growth; she moved from a life predicted as dependent to one of growth, individuation and accomplishment.

The second redemptive scene, the turning point scene, occurred in her adult life and involved self- awareness, or to use her word, “rethinking” that refocused her future direction. Since adolescence Teri traveled a thin line of illegal behavior and dysfunctional behavior related

to addiction. She credited one person (whom she did not identify) as saving her from this future and one specific incident as confronting her with change and her acceptance of this change.

Teri's affect when she narrated this scene revealed that she felt lucky or saved from a dire future. She also possessed the self-insight to know that without her changing her life was headed out of control. Teri described the content theme as one of recovery.

In the McAdams' coding schema this scene scored an additional point for enhanced communion. In this recovery narrative, Teri signified "this person in my life... somebody important" (not a boyfriend)," as the source for positive changes in her life. Additionally, she credited the Lord, (that) "I'm back on the right track... and because of that, you know, I am going to school." In Teri's eyes, because of this communion, "I feel good now... I mean I feel important now... The way I didn't before... I mean, I feel like I can conquer the world now."

Teri's third redemption scene also occurred during adulthood. Here Teri described her herself as a "boomerang kid", "the prodigal son" and "the kid that learned a lesson". This story involved her initial success of moving out of her parents' emotionally tense home to a supported living home. However, this proved short-lived; the agency dismissed her due to her drinking. Rejected as a failure, she moved back home until another supportive living agency accepted her and she again moved out from her mother's overprotection and negativity. At the time of the interview, Teri continued to live successfully in her staff-supervised home.

She admitted that "it took awhile until I got that turning point" and now considered that her life was "coming about" for the positive. In this redemptive scene Teri described herself as having a lot of "potential". This scene reiterated the theme of fighting for positive growth and resiliency despite setbacks.

In this redemptive sequence Teri made the direct connection of her problems with the (lack of) control of her substance abuse. Similar to the previous redemptive sequence, the content of this narrative was recovery. Teri identified her life in recovery terms; she understood the 'boomerang' trajectory of sobriety and referred to herself as the 'boomerang kid.' She entered recovery due to her own strength, the support of friends, and the Lord.

Rose Stanton

I met Rose (Caucasian, age 56), twice in her apartment for approximately ninety minutes. Rose resided in a large multi-unit complex operated by a supported living agency. She sat in a large recliner amidst a crowded one-bedroom apartment, where she had lived for eleven years.

She proudly showed me her new 24-inch flat screen computer and many of her family pictures that hung on the walls. Rose received case management and homemaking services support from the DDS agency.

Both on the phone and in person, Rose expressed concern for the interviewer, cautioning me to be careful because of the heat emergency. During the interview, Rose spoke earnestly and with pride about her life; she added many details that painted a vivid picture of her life story. For example, in recalling her math and budgeting skills, she stated, “I’m always ahead (sic) person. I always like to plan everything out.” She proudly added, “...I don’t have a payee at all.” As evidenced by her voice tone and directness in answering the questions, her affect was calm and confident.

Rose’s day consisted of socializing with other residents, talking with her homemaker, going to medical appointments and watching television. Her social calendar appeared full as she rescheduled her second interview due to being “too tired” from attending her local parish’s church festival with friends. Rose stated that she retired from a sheltered workshop and received her father’s Social Security based on her disability; she explained: “...they said I was very slight, slight retarded...”.

Regarding her religious background, Rose described herself as “I’m a half-breed, half hillbilly, half Kentucky or Jewish”. Religion figured significantly in her life story, and she often referenced religion, such as, someone was Jewish or Christian or Catholic in her story telling. She stated, “I was raised in the church from age of five years old. My dad used to go down to the Wooden Shoe and gamble and play ball on Sunday... my dad sat me down on the [church] steps and took off. ...And that’s how I got involved.”

Rose’s father was Jewish but “got saved at the age of 35 years old, went and quit drinking, smoking and everything. My father knowed that Bible back and forth”. Consequently, Rose claimed a mixed religious identity:

Well it was different because we weren’t- we never studied the Jewish inheritance (sic) but my dad always say’s he always Jew. I forget how he worded it. You never give up your inheritance, what you’re born with, you’re born with... he used to go to the Hebrew Christian Alliance.

Major family tensions originated because of her parents’ different faiths. These tensions exploded at least twice, once during a disagreement at the sitting for her grandfather’s Seder and

when her grandmother “disclaimed” her for being a Gentile. Although raised as a Christian by both parents, Rose lived her Jewish identity during those times that called for tradition, such as a Seder.

In addition to remembering family stressors, Rose’s described her educational experiences as stressful. She described school as the most negative influence in her story, “cause I was tossed around so much to different schools growing up”. Rose attended several city schools; she split her time between “regular” and special education classes but never graduated. At kindergarten age, Rose remembered feeling “very embarrassed” that the teacher chastised her for talking too much, “and that really-my mom says that ruined me for life”. She provided no other school memories. When asked about the lack of teenage memories Rose replied, “I kind of try to block all that out...Cause I don’t even want to think about Billy [her ex-husband] at all, my divorce and now then my sickness”.

Rose married early, “I was an 18 year old dummy”. Her marriage ended quickly due to her husband’s infidelity. She spoke with regret that she wasted her teenage years, “(T)here wasn’t very much in my teenager life. I got married and that’s when I grew up and had to start doing things as a housewife...and it was hard”. Again, religious differences (she was Baptist and he was Catholic) caused problems.

Excluding this short relationship, Rose centered her life first on her family, and now as a middle-aged adult, with her friends and aged mother. Her father died several years ago and her mother lives in a nursing home. Rose worries about her mother and wishes for more involvement in her life. She expressed frustration that her aunts made the medical decisions and that the nursing home was several miles from her home. “I ain’t, don’t have no power over that. I can’t even take her out and that’s what makes me upset...”

Throughout her life, Rose considered her mother strong, determined and oftentimes unyielding. Her mother’s resultant parenting style produced a daughter “who grew up really quick and my mom always blames her on it. That she shoved me too fast and too hard, but when she did that it me very independent nowadays...” Rose remembered that at age ten her mother put her in charge of laundry. She explained that she “ruined every one of my clothes...and I had to wear them...Whatever I ruined that’s what I had to wear to school... I was very determined I was going to do these things and it was so funny, but it all turned out good.”

Regarding her relationship with her father, she proudly described that, “I had my Dad wrapped around my finger.” The time that they spent in church activities solidified their relationship which she fondly remembered:

we were a family orientation even though Dad did drink back then and we really got more closer when he got save and started going to church... We used to take care of the satellite church at Peak Kennedy and we'd go out on a bus ministry on Saturday.

As an adult Rose valued her independence, which she learned from her mother. From her father she inherited the pleasure of communion or relationships. She combined these two characteristics, in her passion for mentoring the younger residents, for example, teaching them math and budgeting. She wanted to continue that role, “I would like to teach people how to-teach them what I know and how I, how I learnt, the way I learnt and [pause] to be self-sufficient for themselves and that way they could be like I am”.

Portrait Specific Interpretation – Rose Stanton

Internal validity. Rose presented a coherent and consistent life story with central themes present in her memories. From early childhood to adulthood, her narrative wove themes of strong communion and agency. She had no difficulty understanding the narrative interview or quantitative questions.

Interpreting the narrative. From a communion standpoint, Rose narrated with a theme of unity. She recalled happy memories of weekend Greyhound bus trips to her aunt's home, where they went “to the movies, and drive-in and they'd have fireworks and I was always scared of fireworks and my aunt and I we got back in the car... That was really fun.” At home, she also felt loved by her parents while witnessing intergenerational conflict, parental conflict and the erratic behavior of an alcoholic father. In the process of her identity making she gained from her mother a strong sense of agency and independence she greatly valued. As early as age three, Rose remembered when she wanted to run away that her mother helped her pack and sent her on her way. Importantly, a short time later, she reunited with her mother who came looking for her. These early years provided her with a sense of independence with a safety net. Rose's relationship with her father largely provided her with a firm sense of communion, despite the turmoil caused by his alcoholism and extra-marital affairs.

Lastly, Rose's sense of self contained a strong theme of religious identity. She possessed and incorporated a complex background complete of Jewish tradition, Christian fundamentalism

and Catholicism. Rose identified more as an individual from her generational historical socio-cultural local community than as an individual with an intellectual disability.

Scores: LGS, GBC, SWLS. Rose's LGS score was almost 70% lower than the overall sample score and her GBC score 80% less than that of the overall sample. Her SWLS score more closely matched the overall sample. (See Table 4.1)

Scores: agency/communion. The number of agency and communion themes found in Rose's story closely matched or equaled the overall sample. (See Table 4.1) Similar to the overall sample, Rose's most frequently occurring agency subtheme was achievement and responsibility. However, the communion subtheme of unity/togetherness appeared considerably more often in Rose's narrative than the overall sample. (See Table 4.1)

Scores: redemption/contamination. Rose's life story produced more contamination and less redemption scenes than the overall sample. (See Table 4.1) The first contamination story involved a confrontation between her mother and father.

Well, dad was supposed to go get a half a gallon of milk for me. Mom waited and waited and waited and he never did come back. So, she got her robe on, grabbed me and we went over to the Wooden Shoe and dad was sitting with a big blonde. Mommy said, "Get your..." and I can't say the word she said, but it wasn't real nice. ... Boy that was one time I've seen my mommy mad. She went stomping out of there and back home.

The second story involved the culmination of a long-standing tension between Rose's parents and the paternal grandmother. The Jewish grandmother disowned Rose, the product of a mixed religious marriage. Rose remembered that at age eleven she overheard her grandmother say to her mother, "(W)ell I don't have anything here". Rose's mother did not answer Rose's question about what that meant. Rose, however, cognizant of previous tensions, perceived it as "... I wasn't good enough for her, other grandkids were better than me and all of them been divorced and got a bunch of kids now which I don't respect them". Her grandmother left on a trip and sometime later returned "in a box". Rose continued the memory and stated that the incident, impacted "my life a lot. ...I mean I'm 56 and I can remember that. Uh, it really had an impact...in some directions it made me harder towards people...I don't let my guard down."

While the contamination scenes centered on communion issues, Rose's three redemption stories, which spanned her life, focused on agency. The redemption scenes contained the content theme of growth and emphasized her independence. Rose named the childhood redemption

scene as her lowest point. This scene recalled when her mother “had to go to work and make money cause dad would gamble and smoke and all the times drinking...”. And while she resented being pushed to grow up at age ten, it “made me very independent... I was –I’m a very determined- I was very determined I was going to do these things [laundry]... but it all turned out good.” At an early age, Rose grew from negative experiences forced on her; she reframed these negative experiences into opportunities for independence and agency.

Rose’s second redemption scene occurred after her divorce. Rose reinterpreted her negative marriage, subsequent divorce, and “days of being wild” as learning opportunities for growth and resultant individuation. She explained: “Well, I grew up, I started taking care of myself after my divorce. I made a home for myself and I didn’t have to depend on my mom for everything...”.

The last redemption scene centered on her successful efforts during a flood in her previous apartment building and the move to her present home. At the time of the flood, “(E)verybody lost everything”. Rose called the Red Cross and “got them to come down and place the ones that needed a place to live... And if it hadn’t been for me calling... If I hadn’t that house would have blew up.” When asked what the story said about her, Rose offered, “It really gave me a lot of steam (sic) to do things. I know exactly what I was doing and I thought quick...”. In addition to Rose’s psychological growth, she moved to her current and safer apartment building and began to receive services from DDS; matched with a case manager who encouraged her independence and decision-making skills.

Research Areas Addressed

The above portraits represent a range of demographic characteristics and life experiences which meaningfully influence the identity making process. For purposes of this research, the common features, or patterns of the narratives, are conceptualized through the use of redemption and contamination, agency and communion, and generativity and stagnation. In addition to these concepts, the methodology allowed for the surfacing of other factors to present themselves as influences to the identity making process. The specific marker of disability as an influence on the identity making process was also explored.

The findings are reported using the total sample for comparison. Subsequently, differences and commonalities between the higher and lower generativity groups are presented.

Redemption and Contamination Findings

An understanding of an individual's self-hood or personal identity occurs in the exploration of redemption and contamination themes. The themes of redemption and contamination provide the connection between the remembered experiences and the self-understanding or psychological reconstruction of the experiences. Experiences re-membered within a redemptive context promote positive psychological health and movement. Contamination stories are those re-membered as spoiled or ruined moments. Cumulatively these contamination memories may produce a future path for stagnation and poor mental health. (McAdams, 2006b)

Redemption. Overall, twenty-four percent, (35 stories) of the total stories (145) analyzed yielded a redemptive theme. Eleven of the twelve interviewees narrated at least one redemption story while three, Andy, Rose and Greg, also narrated contamination stories. Carl did not narrate a redemption story. Twenty nine percent of redemption scenes were narrated within the turning point scenes, 23% within the low point scene, 17% within the adult scenes, 17% within the childhood scenes, 9% within the adolescent scenes and 6% percent split evenly between the religious and wisdom scenes. (Note: the turning point scene, low point, religious and wisdom scenes do not detail the age of occurrence.)

Within the redemption stories, content ranged widely. Employing the categories from McAdams' Coding System for Redemption Sequences, content was organized by psychological or interpersonal growth, learning, recovery and improvement. (See Appendix F for further explanation of categories) Over one-half (57%) of the stories contained the content theme of psychological growth. Other content themes included recovery (21%), learning (14%) and improvement (7%).

The redemption story may score additional points for possessing enhanced agency, enhanced communion and ultimate concern. (See Appendix F for detailed description) Five individuals (Greg, Kevin, Marlene, Teri and Alice) scored additional points in these areas.

Categorization of 35 redemption scenes by age range yielded the following: 31% occurred during adulthood, between the ages of 22 and 45 years, 29% occurred between the childhood years, 6 and 12; 20% occurred after the age of 46 years, 14% during the adolescent years of 13 and 21, and 3% occurred in early childhood before the age of 6 years. There was an unknown age in one redemption story.

Contamination. Of the total stories almost 3% carried a contamination theme. Three of the four contaminated scenes occurred within the childhood scenes (between the ages of 6-12), the fourth story occurred within the wisdom scene. The wisdom scene occurred during Greg's mature adult years.

Examination of Themes by Scene. Deeper, or thicker descriptions of the themes of redemption and contamination occurred with the examination of the turning point and low point scenes. (See Chapter 3 for the decision making process regarding choice of scenes.)

Turning point scenes. The large majority of turning point scenes (10 of 14) revealed themes of redemption signifying a proactive and positive identity making process. The individuals remembered their turning points with a sense of psychologically moving from negative to positive inner space. Religion and recovery from alcoholism or drug addiction were evident in the redemptive turning point scenes. Three of the stories included religious narratives, and two stories included recovery content related to drugs and alcohol. Four of the scenes involved the interviewee initiating a behavioral change from a self-defined negative situation (such as alcoholism, panic attacks, cheated out of money, and dependency on family). No contamination themes were evident in the turning point scenes.

Low point scenes. How an individual ultimately perceives and internalizes the low point experience speaks to one's sense of personal agency and internal working model. Twelve individuals narrated 14 low point stories. Eight of those 14 stories contained redemptive themes.

Thirty-eight percent of the redemptive low point scenes occurred during the childhood years between the ages of 6 and 12. Twenty-five percent occurred during the adult years between the ages of 21 and 45, the remaining redemptive low point scenes were evenly divided between the mature years of 46 years and older, adolescent years between 13 and 20 and one unknown.

One-half of the redemptive low points scenes contained content related to the death of a family member. Two of the stories contained content related to the interviewees' parents' reaction to the diagnosis of Down syndrome and the impact felt by the interviewee. One story related to drug addiction and the other story centered on the interviewee's memory of losing her childhood freedom and becoming independent related to her mother's return to work.

Influences on Redemption stories. Presented earlier, the portraits explored the redemptive themes for each individual. Kevin and Marlene's life stories, explored through the lens of redemption, highlight the similarities and differences of redemptive themes within the

context of the individual's life story and suggest the importance of structural characteristics in the making of a redemptive identity.

Marlene. Marlene's narrative exemplified a rich redemptive life. Five of her stories, slightly more than one-third of her total stories, contained a redemption theme, with all occurring during her adolescent and young adult years. These redemption stories also contained enhanced agency and ultimate concern.

Marlene narrated the following scenes as redemptive: a low point scene, two turning point scenes, and a spiritual/religious scene. Marlene's redemptive stories shared the common themes of openness to experience and reframing the negative into opportunities for positive change. Many of the redemptive scenes reflected her self-motivation toward psychological growth and movement toward an agentic adult identity. These identity-making themes began within the safe environs of a nurturing, socially conscious and religious family which encouraged Marlene's agency and self-exploration. Consistent with her other identity-making stories, she framed her redemptive stories in current societal issues, such as the terrorist attack of September 11, 2001. As a result of this historical event, she challenged herself to better understand the Muslim religion. This narrative also spoke of her entrance into the larger moral world of ultimate concern.

Kevin. Although raised with different socio/cultural and racial life experiences, Kevin also produced a redemptive narrative. One-third of Kevin's stories echoed a redemption theme, with an additional score for enhanced agency. Like, Marlene, he defined his low point as the death of his grandmother and, reflecting his inner sense of hope, he reframed this low point as a redemptive story. This scene also was consistent with his life theme of responsibility and development of a moral character.

All of Kevin's redemptive scenes consistently echoed his identity as a survivor. The scenes also spoke to his desire to feel respected and to be visible or known to others in a positive light. He exhibited a resiliency to "life on the street" and was open to help of others to get off the streets. Kevin called upon his memory of his grandmother, wanting him "be good". The positive influence of others reinforced his internal working model of possessing strong moral and citizenship values.

Influence of structural characteristics on the redemptive identity. In these two redemptive narratives one witnesses the influences of race and economic status on the identity

making process. Kevin and Marlene offered life stories that were high in redemptive content and provided texts for comparisons and contrasts. Both individuals experienced strong positive family attachments. Marlene benefited from several close family attachments that nurtured her creativity and self-exploration. Kevin experienced one primary attachment with his grandmother, who fulfilled his basic psychological needs of safety and security. Through his memories, Kevin keenly articulated his and his grandmother's ongoing challenge for decent housing and a safe environment. He declared his life a success because he remained out of trouble, people respected him and he treated others with respect. He identified himself as a survivor.

Marlene's family did not struggle with life's basic needs and laid the developmental groundwork for her identity as an artist or teacher. She considered herself a success because she increasingly became more engaged in the larger world through her artwork, teaching, and religion. One of Marlene's redemptive scenes reflected this moral engagement as ultimate concern.

Both identified their low point as their grandmothers' deaths. For Kevin, this experience transformed into a redemptive sequence because it offered a venue for others to see him as a responsible and loving grandson as well as a reason for him to stay "off the streets". Through his grandmother's illness and death he gained self-respect and self-validated that he was a good person.

Marlene's grandmother's death also provided her a time for self-reflection and a commitment to honor her grandmother's artistic gifts by developing her own gifts. For both, Kevin and Marlene, their intimate connection to their grandmothers meaningfully impacted the identity making process for them. Like his grandmother, Kevin was a survivor. Like her grandmother, Marlene was an artist and person of the world.

Kevin lived his life with cautious hope and optimism. He experienced others mistrust, prejudice, and doubts about him as well as the unpredictability of daily life for a financially struggling African American male. Marlene, a young Caucasian financially secure woman, lived her life with confidence and openness to experience.

While cautious about others but with hopes to make his life better, Kevin exhibited a willingness to allow persons into his life. In his redemption turning point scene, almost homeless, Kevin opened himself to help from community organizations. He valued that caring and help on a personal (communion) level. Those affective connections nurtured his personal

identity as a “good person” and his need to feel respected and liked. Integral to trying to “get the bad times farther away... and “to better my life” was his openness to accepting the help of others. Kevin’s resiliency-his capacity to elicit and accept help or support from others (Murphy, 1974) proved key to his redemption story.

For Marlene, her turning point scene, also redemptive, stressed her agency and highlighted her individual strategy for change. She recognized that her panic attacks and anxiety inhibited her ability to achieve her goals and thus she initiated counseling. In Marlene’s turning point she instrumentally, rather than affectively, related to others.

Kevin’s and Marlene’s agency and communion scores for their overall life story add evidence to the differences discussed above regarding their redemption stories. Kevin’s overall life story reflected a communion rich narrative; he scored more than twice higher in communion themes than agency themes. Marlene’s agency score was slightly less than twice her communion score.

Contamination Stories

The comparatively small number of contamination scenes offered little data for comparison. Three individuals narrated four contamination stories. Rose narrated two, and Greg and Andy each narrated one story. Rose’s stories occurred during her childhood years, her first at age 3 and the second at age 10. Her first memory involved her mother finding Rose’s father with another woman.

Her second memory concerned her paternal grandmother “disowning” Rose. Her grandmother, a Jew, rejected Rose, a product of a mixed religious marriage. Rose remembered the incident as her grandmother leaving their home and declaring, “I don’t have anything here.” She remembered feeling that “I wasn’t good enough for her” and now at age 52 she believed that this contamination narrative left her feeling “harder towards people. I don’t let my guard down. I’m not very- I don’t trust...” These contamination stories resonate with issues of rejection and trust. From childhood, religion foregrounds many of Rose’s meaningful life experiences, positive and negative.

Greg’s contamination scene, which he narrated as his wisdom scene, centered on his well- intended gift of money to a drug addict to buy groceries. However, this positive action turned negative when the individual “went and got high”. This contamination story echoed earlier content themes of drug addiction and recovery.

Like Rose, Andy remembered a significant childhood memory as a contamination story. The content of the story centered on a bicycle accident innocently caused by a friend. From his reconstructed memory, Andy identified himself as someone who was “too sensitive” and risked being hurt by others. From his childhood physical injury, the psychological injury of being “too sensitive” began to take shape. This identity making memory provided a foreshadowing of his identification with the “underdog” as one who displayed sensitivity and oftentimes was unprotected.

Agency and Communion Findings

If one considers the stories of one’s childhood as proof of a remembered past and the stories of an anticipated future as the metaphoric bookends of a complete life story; then one explores those stories for themes of unity and purpose in one’s life. This unity and purpose shows itself with the concepts of agency and communion. Communion and agency and their subthemes were explored employing the categories from McAdams’ Coding System for Communion and Agency (See appendix E for further explanation of categories.)

The interviewees shared a total of 33 childhood stories. Ten of the twelve interviewees narrated their early stories with family as the central focus. This foregrounding of early childhood memories fits into the “typical” human development model of family as significant to identity development. For most, the early family stories included memories of positive feelings about shared activities. A few (Greg, Teri, Irene) narrated these family memories through negative feelings related to events associated with alcoholism.

The early childhood memories of Alice and Otto centered on stories which stressed individual agency within a hostile environment, such as the school or the religious structure, rather than primarily family relationships. This pattern found in the early childhood memories followed the overall life stories of Alice and Otto who scored highest in the percentage of agency content themes. As discussed in the Portraits, much of Alice’s and Otto’s adult years centered on the generative actions of advocacy. Irene, the third interviewee, who narrated early childhood scenes with an agency theme, self-described a life theme of self-sufficiency and independence.

Those stories, which lacked communion, were recalled by men (Greg and Carl). One-third of the interviewees narrated their childhood stories with at least one theme each of agency and communion. Most often, the communion subtheme of unity and togetherness (10) appeared

followed by love/friendship (6), caring/help (4) and dialogue (1). (Note scenes may earn a theme score but not a subtheme score, or may score more than one subtheme.)

Examination of themes by scene. Further exploration of the themes of agency and communion occurred with the examination of the earliest childhood, other significant childhood memories and future scenes and high point scenes. (See Chapter 3 for the decision making process regarding choice of scenes.)

Earliest childhood scenes. Each interviewee recalled an earliest memory. Of interest, two-thirds of the earliest memories were narrated without an agency theme. Alice's earliest memory contained more agency subthemes and communion subthemes than all others' stories. Alice, Otto, and Irene, among the older interviewees, narrated an agency theme. For Alice and Otto, they connected their early personal histories directly to their advocacy work as adults. Irene's personal identity contained strong elements of self-sufficiency and independence. Within these agentic stories were the subthemes of self-insight and achievement and responsibility.

Every interviewee narrated their earliest memory with at least one communion subtheme. Unity and togetherness and caring and help most often defined the communion experience, with dialogue and love and friendship in third and fourth order. Only Greg's story contained neither agency nor communion. Unlike the other interviewees, Greg's earliest memory came at age 14, quite late in his developmental process. He remembered that he sat alone and realized "(I) (D)on't have no family". This memory lacked communion and agency; rather it portrayed a passive adolescent filled with hurt and believing that "it's my fault" and that "(N)obody cared".

Other significant childhood scenes. In addition to their earliest memories, twelve individuals shared twenty-one significant childhood stories. Of the five individuals whose stories did not contain agency, four were women. For those who narrated with agency, the subthemes in order of frequency included achievement and responsibility (7), power and impact (5) and self-insight (2). No one narrated a status and victory subtheme. Stories narrated by the men, Greg and Carl, lacked communion. One-third of the interviewees narrated their stories with at least one theme each of agency and communion. Most often the communion subtheme of unity and togetherness (10) appeared followed by love and friendship (6), caring and help (4) and dialogue (1).

Future scenes. Ten interviewees provided a future scene for their life stories. Ninety percent of the individuals told this scene with agency and/or communion. Only Andy's future scene contained no agency or communion. Andy projected an uncertain vision of his future; passive in his expectation for the future, he stated that he did not believe that "things will change that much". Three of the individuals (Greg, Teri, Rose) imagined their future containing agency and communion themes. For the remaining seven, four women envisioned life from an agency theme, while three interviewees (Irene, Ed and Kevin) envisioned life only from a communion perspective. Four persons (Andy, Alice, Vicki, and Marlene) shared no vision of communion in their future scene.

Within the agency narrative, achievement and responsibility dominated (6), followed by power and impact (2) and self-sight (1). Within the communion narrative, caring and help (3) and love and friendship (3) shared dominance, with unity and togetherness (2) closely following.

High point scenes. All individuals narrated at least one high point scene, yielding a total of 22 scenes. No one content theme emerged from the high point scenes. In order of frequency the following themes appeared, recognition of others, either formally or informally; feeling of closeness with family or friends; helping others; transitional events, such as moving away from family or buying a home; and starting work.

Sixty percent of the total points scored for agency and communion were scored within the agency category, suggesting that a sense of agency dominated the identity making process when considering the high points of these individuals' lives. One-half of the individuals narrated disability content in their high point scenes.

Generativity and Stagnation Findings

"Generativity is an adult's concern for and commitment to promoting the well-being of future generations" (McAdams, 2006b, p. 4). By definition, stagnation suggests lack of movement or involvement. A stagnant person is "unable to generate outcomes that extend their care and commitment to future generations" (McAdams, 2006b, p. 220). A stagnant person finds "it very difficult to ascribe overall direction and purpose to their lives" (McAdams, 2006b, p. 217).

Rather than presenting findings from specific scenes, the findings are presented via individuals' life stories. (See Table 3.2 for explanation of the decision making process on how and what data to analyze to address generativity and stagnation.)

Carl (age 27). As a young adult, Carl’s narrative focused on the development of a personal identity rather than the expression of a developed identity with resultant generativity. From his account, Carl saw himself primarily as a young man attempting to establish a sports career. He lived more in the moment with friends and family rather than contemplating his legacy.

However, although he described the theme of his life as “(B)asketball...It’s great, my life is good because of everything”, he also articulated his values as an involved American. He described his political values as “war and troops” and stated that they “fight for our country to ...(S)ave us against terrorists”. He stated that he believed in supporting the troops and acted upon this belief through his volunteer efforts of sending cards and packages to troops stationed overseas. Witness to his deep patriotism, Carl dreamed that he would be a soldier fighting in Iraq in his “made up” movie.

Carl wanted others to see him as an advocate and he considered himself “a good leader”. He proudly talked about his work “to fight for my rights” and his role in eliminating the use of the “R-word”. He credited his current program with giving him the opportunity for such community involvement. He described his role as a program ambassador as “about business and leadership” and a precursor to board membership.

When asked to describe what his movie would show, Carl stated “(T)he movie, is respect movie. My movie with being **respect** (his emphasis)”. This statement augmented his earlier comments about his advocacy work directed toward removing the “R-word” in government.

Carl attributed no religious beliefs to his generative actions. When asked about his beliefs he stated simply, I “believe in God and Jesus...If I die, I go to Heaven.”

Carl anticipated his future to include “(C)oaching, business, coaching girls’ basketball and business”. His legacy would center on the status and victory of his coaching achievements.

Irene (age 39). Irene revealed more about her desire for generativity in her vision for her future than in her narratives centered on her present life. The extensive detail in which she articulated her hopes substantiated the depth of her feeling about a future generative life. Throughout her interview, Irene narrated a number of challenges that she faced. For Irene, she applied generativity framed solutions to these challenges.

She considered her greatest challenge “...to finish college, get my degree and show some of these police officers the meaning of the word ethics”. Irene’s motivation to positively impact

the criminal justice system arose from the negative experiences that her brother, who was deaf, endured with police as a result of their lack of knowledge and sensitivity about people who are deaf.

Irene also considered her (future) college graduation as a contribution to the positive impact of educated women in society. For Irene, her graduation showed,

...that women can do just as much as they can and have a –can do- rather than women always- men thinking that women have to stay at home and just be-take care of children all the time and have always have to be pregnant. I think that men need to really realize that women can do just as much as men can do and be able to handle just as much as they can handle and work just as hard they can.

Exploring the theme of generativity as it related to her sense of social responsibility or commitment, Irene described her political and social values:

Well, my strongest issue is being able to [pause] work and handle and be able to help other people that need to know how to – at least be able to help people find jobs. And [pause] just know that the president is doing the best that he can to run things the way they should be or trying.

Irene's hoped for future extended to generative goals with her son and future husband.

These goals included:

Uh, I would be getting married, um [pause] living with my husband and my son. Um, just having a happy life and going on and doing things with my husband and my son. Going to the – taking my son to the beach and letting him get through school [pause] and letting him decide what he wants to do with his life...“Um, [pause] my son growing up, getting through high – my boy in high school, graduating from high school, going to college, getting a degree, him having his own children and [pause] being - having – doing whatever he chooses to do with his life.

Irene's self-declared most important value matched her future story:

The most important value is teaching my child, son, how to be able to be independent, not having to depend on a lot of people and learn how to handle his life and be able to do what he wants to do in his life. That's my most important value for him.

Irene attributed any changes in her values over the years to becoming a lot stronger and I'm learning now that I can do whatever I set my mind to and do whatever I know I'm

able to do. I'm not going to sit and push myself knowing that I can – there are certain things I can and I can't do. And I know that I can as long as they're a lot of – I have the strength and the muscle I can do whatever I set my mind to. And I'm willing to do whatever I can to make my life a lot stronger.

In another narrative sequence Irene again acknowledged that now as an adult I think I've learned a lot of different things that I really didn't even know. I learned how to keep up with my – learned how to control my disabilities, my – I learned how to control my health problems. I also learned that – how to be on my – learn to deal with things on my own. I learned how to handle living on my own and I also learned how to deal with having a lot of different friends – not having a whole lot of friends but learning how to be able to go and do things that I needed to do and basically the more I learn the happier I'm becoming basically.

In these declarations one hears her determination and motivation for self-understanding with resultant positive change. She sought to understand "...how I was raised, um [pause] how I dealt with being raised and basically what it was like to be raised as the oldest child". She reinforced this intent when she described the moral or theme of her life as,

Um, learning how to deal with disabilities, learning to at least talk your problems out, learning how to deal with things that you thought you would never be able to handle and just [pause] knowing how to handle your whole life.

Greg (age 61). Greg regarded his life as one of redemption; his life once haunted by homelessness, drugs and alcohol transformed into a generative life - thanks to Jesus. He lived his life's theme, "(D)on't give up if you messed up your life" from a personal survival standpoint as well as a mantra for his work with persons who were substance abusers and/or homeless. While Greg believed that "you can't depend on nobody else", he also believed that you have to ask for help if you need it. This value stressed a strong sense of responsibility while recognizing the connection to others. From his personal experiences Greg named a few important persons in his life, a "bum" from his childhood who protected him, a "missionary lady" who saved him, and Bill, his case manager of several years. He stated that it was "really good in my life that Bill come into my life, that was **really** (his emphasis) good in my life...I got bummed and Bill helped me out..." "...I got somebody I can count on."

Greg's work with persons with addictions also illustrated his belief in self-responsibility while remaining open to help. He did not push himself onto others but offered his help. He also worked to empower them to believe in themselves. As he described his approach:

When I help like other drug addicts I tell them name five things about yourself that you like. People don't know that. You go get a drug addict and name five things you like.... If you were a bum maybe get two or three, that'd be it. I ain't had a drug addict get all five of 'em.

Through Greg's own behaviors he chose a generative rather than stagnant life. He claimed his responsibility to become and stay sober and moved beyond his own needs to helping others. He embodied his religious belief that "I feel like God wanted me to help somebody there, God put somebody in my life to help them out." This revelation of being part of God's plan came at age nine after a failed suicide attempt, and has not changed since then.

"God's plan" centered on helping persons like himself, who were poor, homeless and addicted. Greg acted upon his beliefs by sharing his home, money and food with others, working with persons who lived on the river bank, repairing small appliances for friends, and participating in formalized advocacy work to access or develop housing for persons with developmental disabilities.

Greg possessed a political sophistication regarding power and access to resources. He understood that "funding people don't give us much as they used to" and that he needed to "advertise" his cause.

Greg lived his motto, "don't talk about it, do it", oftentimes using his own money to help others. He knew that God would repay his generosity. "God will give it back to you sometimes more than what you give."

In narrating his future scene, he imagined himself helping orphans. He also hoped to write a book about himself.

Alice (age 63). Alice stood out as a clear example of a generative life. In her life story narrative, she spoke eloquently about her values reflecting a purpose larger than her own life. In her stories, her behavior matched her expressed values and intent. As she declared, she will continue her advocacy work with "people like me" "'til I go in the grave".

Alice valued the knowledge that she first came to know and love herself before others knew and loved her. The qualitative analysis of agency themes, confirmed her strong motivation

to know herself; i.e. self-insight scored as her most frequent agency theme. “Know Yourself and Take Your Power” provided her life’s purpose. She stated that advocacy work called her because she wanted to “(T)each people about their life” and “how to do whatever they want to do.”

Alice exuded confidence of knowing oneself. When asked to describe her movie, she stated that it would show herself as, “the greatest person on earth”. Her long advocacy career reflected her passion for others to “know that you have power”. She most valued her direct work with persons with disabilities to help them find their “own gifts”.

A firm believer in Jesus and his calling to serve others undergirded Alice’s strong sense of unity and purpose. She considered life precious and that one should “(D)o all you want to do, before Jesus say, ‘it’s time’.” Alice lived her religious values, not only in her daily life of treating others with love and respect, but also in her church missionary work.

Alice’s life story and personal identity aligned closely with her values, motivation and behaviors. Her generative actions included public speaking, working as a teaching assistant for children with disabilities, membership on influential policy making committees and boards, writing about her life and lessons learned, mentoring, and missionary work.

Significant to Alice’s legacy was her strong belief and resultant action in serving as a role model and mentor. As an adult, Alice became close with a female mentor who was disabled. As Alice remembered, “(S)he said, ‘you know that you can do something better than what you’re doing.’ And I said, ‘Ha,ha,ha,ha,ha! And then now where I’m at.’” From this experience Alice understood the importance of a strong role model and personal champion and subsequently devoted herself to doing the same. In particular, Alice stated that she shared her wisdom and friendship with a young woman, also disabled. In Alice’s words, “my wisdom, when I talk to May, I tell her a lot of stuff... I think I tell a lot of the wisdom I want her to know, what I want her to learn. It’s funny because she is 34 and I’m 63...”

In her broader advocacy efforts, Alice considered her generative work as acts of love, “I share my love...” She stated that “...that I love to go places, teach people the wisdom... for themselves.” In her narrative, she related several instances of receiving positive feedback regarding her work. She recalled “when a month later, two later, a year later, when they come to me and says Alice, ‘I’ve got the power’”.

Alice remembered another experience,

when one day I talked to the third, the second graders and the third graders. And one little kid came up to me and said ‘hug me’. And I can’t remember what she said to me. I was high for five days... I will never forget that kid hugging me after my talk.

Alice’s sophistication in understanding the sources of power for change yielded another meaningful finding regarding her expression of generativity. Alice directed her change efforts in two locations. In one location, through her educational and mentoring efforts, she worked toward the self-empowerment of persons with disabilities. She expressed her sense of accomplishment in this area when she recounted the pride and happiness that she felt when the audience repeated after her, “we’ve got the power. We’ve got the power to do it. We’ve got the power.” Alice understood that those who “...don’t have the power; they don’t know what they have...” And if you don’t know what you have, “...you will think you always back there”.

Alice’s located her second change strategy in the seat of recognized power structures in disability services. Here she became involved in several local, state and national boards, such as, the state developmental disabilities council. In this environment, Alice understood the importance of networking, as she recalled being with the governor when he signed legislation, “outlawing the R-word” in all state business. This is the same struggle described earlier in Carl’s story.

Upon her self-review of her journey to advocacy work, Alice stated that as a younger person, “...I didn’t think about anything like that. ...I didn’t know how to do stuff.” She stated that she wasn’t “advocate-like”.

Marlene (age 26). At the time of the interview Marlene’s young life already contained a strong generativity theme. She primarily identified as an artist and teacher to young children with autism and she exhibited a passion for leaving her creative mark in the world. She identified the theme of her life movie as “hardships and challenges along the way and I’m an artist.”

In Marlene’s internal belief system she named herself a “failure to thrive baby” who developed into a creative, motivated, open-minded and curious young adult. She lived by the maxim that one must be “willing to change”... and “willing to step forward”. Complementing the generativity theme apparent in her career choice, she narrated stories of her late adolescent and young adulthood that reflected emotional and psychological development of self-

understanding, such as, moving out of her mother's apartment and into a supported living home, initiating counseling and joining a women's writing group.

As discussed in previously analyzed stories, Marlene's family, specifically her grandparents, lived and modeled a generative narrative. Marlene's strong Quaker upbringing and currently held Quaker beliefs greatly influenced her identity development and generativity. She credited her faith with challenging her to understand and to respect all people. She explained the importance of looking past barriers which she described as, "skin color, different religion, um, or like, or like different, um background. So, so basically we should have a heart to see everybody around, around us the way Jesus would see it".

Marlene's behaviors and self-insight reinforced this generative motivation. She recalled her personal experience with racism as the time when the Ku Klux Klan attempted to place a cross in the downtown area of her small suburb to "scare off black people". From this life-changing incident, she challenged herself to better know African Americans and dated a young African American male peer. As she described, "...I just said, well, I want, I want to try dating a black person and see whether that helps. Um, and it really did. It, it, it opened me up, um really there's something behind the skin in everybody".

Marlene also narrated a strong social commitment to understand persons of different religions and cultures. As a reaction to the American watershed event of September 11, 2001 terrorist attacks she challenged herself to learn about Muslims and to find a commonality with them.

In many ways, Marlene's life story as an adolescent and young adult mirrored the moral development of typical youth with the favorable outcome of a concerned and socially aware citizen. Marlene's social commitment to living as a good citizen of the world also extended to her concerns and actions regarding global warming, military warfare, humane treatment of animals and anti-smoking. As a high school student involved in the D.A.R.E. program, she wrote to government representatives about her anti-smoking beliefs and urged legislation on this issue. Regarding her concern for animals, she narrated a story in which she ate frog legs "because I wanted to eat something exotic.... And I hadn't eaten any bugs, so I figured a frog's the next best thing". However, she later felt guilty because she discovered that it was an endangered species. As she explained:

that the animals, that inhabit this thing are, um, are crucial to this world... So, I go to, go to, go to eat these frog legs, and then I felt bad for the frog when I, when I learned that the frog that I was eating was endangered.

Religious, social and political values intersected in her identity as Democrat (which she said was the affiliation of many Quakers) and Quaker. She considered herself a world citizen; thinking and acting in a manner larger than her own needs and wants. On a more daily level of engagement, Marlene articulated her desire to take reside in a community where she could enjoy a coffee, a haircut or music.

Marlene's commitment to change and life-long learning also extended to challenging herself in more personal areas, such as, public speaking. She enrolled in a film making class to confront this fear. While confronting this personal challenge she co-created and acted in a film that positively portrayed persons with disabilities. As she stated, "(F)inally I said this is what the world wants to hear and this is what matters...I'd be willing to be anything". Her vision of self-improvement continued with her desire to play piano and to swim.

Marlene's anticipated future fit congruently with her remembered past and perceived present. She imagined herself "teaching high school students how to create art." And again her personal challenge, "(S)o I'm making a leap from (teaching) kindergarten to eighth grade...". Regarding her living arrangements she stated,

I feel like I am almost done here (her shared supportive living arrangement), but not completely...And I still need help...it's gonna be another big change that I have to fight...But one of these days, I'm going to make that leap and it might be when I'm 30, or 40.

The exploration of Marlene's generativity themes yielded the general findings that her family and religious background influenced her commitment to generativity, to looking beyond herself. Her personal mythology of winning the struggle of a failure to thrive baby contributed to her sense of self-empowerment and agency.

Marlene embodied her beliefs in social change, altruism and personal growth. As she quoted her counselor, "... if you don't have the desire to make the change then you won't make the change...".

In the exploration of Marlene's life through the generativity lens, one witnesses the breadth of her beliefs and actions, extending to issues of disability, environmental and health

concerns, racism, and ethnocentrism. As testimony to Marlene's self-awareness as member of a discriminated group, she cognitively linked the struggle of African-Americans to that of persons with disabilities. She made the connection between Africans being treated unfairly as slaves and "people with disabilities were treated just like the slaves in African times". Marlene's personal yardstick for generativity included her successful application of the Golden Rule, her single most important value. When asked to identify her life theme, she focused on her personal and social identity as an individual with a disability. She stated:

people with disabilities can do what they want to. It just takes a little bit more time to like, get into them and like, to realize, fine, um, and then and, and, uh, and then, and it doesn't really help to laugh at different disabilities than you because they could be the best of, um, friends, and you could end up learning from them.

Although in her early twenties, Marlene already engaged herself in generative life. Her strongly held beliefs, motivations and actions exquisitely complemented the other.

Otto (age 65). Otto lived a generative life. Beginning in his early childhood, in the late 1940's and early 1950's, he watched his mother fight for the rights of his older brother, who was severely intellectually and physically disabled. His mother began one of the first Association for Retarded Children chapters and subsequently became a national leader in the parents of retarded (sic) children advocacy movement.

Throughout Otto's life, he felt his mother's influence in his advocacy work. He stated that "I got my fighting spirit from my mom". He narrated his spiritual scene as occurring a few months prior to the interview when he talked to physicians at a Washington D.C. conference. As he recalled, "...I was the only self advocacy (sic) there...And I feel- and I feel like my mama is back of me giving the talk." He continued that he felt her presence,.... Many, many, many times."

His mother also inspired his goal to write a book. During his Washington trip he visited the Library of Congress and saw his mother's book about the rights of handicapped (sic) people. Otto stated that it "made me feel good...I want to write my book and put it there".

Otto's generative script originated in his motivation and action to help his brother, Leo, thus carrying on the legacy of his mother's generativity. With passion and empathy, he vividly detailed the family's visits to the large institution where Leo lived until the late 1980's. With his mother deceased and deinstitutionalization occurring, Otto challenged the legal system of

guardianship and became Ohio's first person with a disability to become guardian of a family member with a disability. He shared this guardianship with the state appointed Advocacy and Protection Services guardian and subsequently served on the state Advocacy and Protection Services' board. Otto understood his legacy regarding this battle when he stated "other people do it today" (i.e. other people with disabilities are guardians).

Integral to this experience of challenging the hegemony, Otto recounted the prejudice that he faced with professionals who considered him incompetent to make decisions for his brother. This theme of resistance and consequent generative action consistently repeated itself in Otto's narrative. He provided additional evidence in his scenes about confronting the state Bureau of Vocational Rehabilitation system regarding its acceptance of low wages for persons with disabilities and non-representation of consumers on its board. He stated that he "(G)ot on a lot of committees in the states...for all kinds of things", not just employment.

Otto's passion for inclusion in the locus of power extended not only to the state powers but also in national and local agencies and in his Jewish religion. Otto served on the board of a national training center. As recounted in his portrait, Otto and his mother successfully challenged the local synagogue in its policy of denying males with intellectual disabilities the right of bar mitzvah. Other long lasting changes in the local Jewish community included the development of a group that not only provided culturally based social experiences for Jewish young adults with disabilities, but also recommended changes for fuller inclusion in the Jewish holidays, such as Passover, and physical accessibility issues. Otto also identified several volunteer community activities in which he participated as a synagogue member.

Speaking as veteran advocate, Otto stated that he now was more selective with committee or board memberships. He stated that, "I don't want to be (a) token member" and feel that he did "not count".

Similar to Alice, Otto directed his generative efforts in a number of directions. As noted above, he worked for a comprehensive, system's change within formalized power structures. He also helped create self-empowerment groups, such as People First, USA2 and Voices that Count. These "disability identified" groups recognized their power and worked to effect societal change. As part of his work responsibilities, Otto often taught empowerment classes to others with disabilities in their workplaces and at self-empowerment conferences. In analysis of Otto's agency categories, his stories contained more power and impact or achievement and

responsibility subthemes rather than status and victory, reflective of Otto's motivation to impact others for the greater good rather than personal status. He verified this altruistic motivation by many of his actions. He cited one example, as "I also help put people on board", i.e. continuing the empowerment process for others.

In Otto's life the redemptive nature of his personal self-identity operated in tandem with his group identity and resultant generative actions. He recalled as his earliest childhood memory a redemptive scene in which nondisabled students belittled him and "all the kids in the special class" and his teacher predicted that "...I can't do nothing and I say to her, 'Yes, we'll make it'." Otto's life exemplified, "making it" and he considered his own success as contributing to the success of others like himself. He interchanged "I" for "we" when considering the future of him and others with intellectual disabilities.

Integral to his personal identity, Otto internalized a sense of specialness: of being able to resist prejudice, to help others and to make powerful changes. Otto shared a story in which state professionals said to him, "We don't want people like you at the meetings". Otto repeated this belief when he commented that professionals, "(D)idn't want us- did want to work with us but they didn't want us on their level." Rather than internalizing the prejudices of nondisabled persons and their attempt to make him "invisible", Otto made himself visible and forced others to "count" him.

Otto shared with other interviewees a passion for educating others about persons with disabilities; and he considered this a valuable mechanism for change. He provided testimonial about his life to school age children and college students with and without disabilities. In his annual discussion with social work students at a local university, Otto encouraged the students to establish an empathetic relationship with their "clients" and offered ways to do this.

I tell the social workers, 'Take your clients out for lunch. Meet them on their level. Learn how to work with them then you'll be a good...Then you learn how they feel ...Be with them', you know what I mean.

Otto shared his experience of talking with teenagers in Oklahoma City who had lost their parents in the bombing of the Federal Bombing. His message to them was, "You can do stuff." And he remembered this talk as "...That was the hardest talk".

The breadth of Otto's generative actions extended to participating on an ethics related committee that addressed issues impacting persons with intellectual disabilities. Again, Otto

extended himself to impact the greater good for persons with disabilities. He offered his wisdom on issues, such as parents' wishes that their adult daughter with an intellectual disability abort a pregnancy versus the daughter's desire to have the child, and questions of "pull the plug off the people...pull the equipment away...". In the first example, he stated " We-I told her (the daughter) no you don't have to do it, here are your rights. So I won her case. Her mom, she never give it to her...I say yes, I agree with you but you can't have-be it's her right to have the kids." In the latter example, Otto stated that he asked the question, "Is the person ready to die or not".

When asked how he became so wise, he offered, "I've helped a lot of people through the years. You know, like working with that girl that call me every day what's her supposed to do." He elaborated that his wisdom came from "the experiences I have. Doing all kind of stuff."

In addition to his mother's life-changing and persistent significance, Otto identified two additional people as key mentors in his life. These individuals, whom he considered good friends, worked as professionals in the disabilities services field and were nondisabled. Otto credited one individual with changing his life from that of a hotel housekeeper to an advocate working in an office. Similar to Alice's experience of being mentored, Otto experienced a moment of "you're kidding" disbelief when he was challenged to a higher calling.

Otto linked his political and social values directly to his passion for and action related to empowerment of persons with disabilities. Regarding his political values, he stated he believed that everyone had the right to vote and shared incidences in which "handicapped people today" can't vote, due to family members not allowing it. He stated that the greatest challenge was "getting out to vote, we want work, bus service" and accessible restaurants. Otto shared an experience when he and his girlfriend, who used a service dog, were refused service at a restaurant. He called the police who informed the owners that Otto and his friend had to be served. Otto stated that "you've got to fight for your rights" "...I've got to..."

Otto framed the struggle for persons with disabilities to have equal rights and full citizenship within the larger civil rights struggle. He expressed gratitude to Martin Luther King Jr., "I'd say thank you to him, Martin Luther King, we've got some of our rights today, more." Otto's appreciation of this civil rights history came directly from his personal experiences of living in an urban area that was a focal point for riots in the 1960's. He remembered police escorts to work during the riots and came away with the belief that "you don't tear good stuff

down”. During the Vietnam War, Otto attempted to enlist and his effort was denied because of his disability. He recalled “that hurt, I’d have love to done that.”

More currently in political history, Otto shared his political opinion about Sarah Palin’s vice-presidential campaign. He stated that he and other “(A)lot of handicapped people in this country asked the same question”, i.e. why wasn’t she taking better care “her boy?” She “didn’t take care of little boy”. He stated that he “would love to see a woman president, the only reason (not to vote for her) is what her doing with her son, not a staff person”. In this political moment, Otto privileged his identity as a person with disability over his identity as a social liberal, i.e. someone who prioritized a woman’s right to choose career over family.

Otto perceived that he had to actively resist and challenge many Jewish traditions in order to identify and celebrate as a Jew. He stated that “I learned through the years in the Jewish religion, (they) don’t want people like us. Religion should treat all people-people should say hi, help them.”

Otto envisioned no slow-down in generative efforts in his anticipated future. He expected to continue committee and conference work and intended to work toward the change of state regulations to mandate the membership of two persons with disabilities on county boards of disabilities. He also wanted to continue his involvement on the ethics committee.

Now as a senior, he expressed interest in working on issues related to his age group. Otto had investigated a few day programs for seniors with disabilities and believed that he was “too high functioning” or “smart” for these programs. He stated that this repeated other times in his life, when for example, there was a “rule about working in a sheltered workshop” and “I didn’t need to do that.”

Also, Otto wanted to concentrate on some personal interests, such as, having a cat and dog to “keep me company” and to set up and enjoy his train set.

Otto’s final thoughts on how his movie would end and the essence of his life theme reflected this pattern of generativity and compassion. He exhibited his maturity with his comment that his values had changed in that he “learned how to work together to get what you want”. He believed that one should “Do a good deed per day. Second, we can do it, people like us, we can do it...”. He stated that his life is “about helping people” and “(J)ust doing it, because I proved who I am.” His most important value was “(H)aving a good life”.

Otto revealed his optimism for the future. When asked what advice he would give a young boy with or without a disability, he offered, “(Y)ou could go to college, do it. Don’t let people tell you no, do it.”

Vicki (age 42). Vicki, one of the younger interviewees, narrated a full life with beginning themes of generativity. Unlike Marlene’s more philosophical life theme, Vicki described the theme for her life movie in concrete terms that focused on her “early childhood memories...work experiences...a living on my own”.

However, Vicki spoke with a sense of agentic accomplishment and pride when she talked about co-authoring a book about public speaking and authoring a story for an edited book written with other women with intellectual disabilities. She shared that writing the book about public speaking confirmed to her that “(T)hat I’m popular”, and that writing in the anthology, made her “...feel confident about myself...I’m proud...”.

Vicki also shared that she carried out her agency’s (the Down syndrome Association) mission to educate the public about persons with Down syndrome. In her role as advocate, she spoke with school children and educated them about herself and in general, people with Down syndrome. As she described, “I go to different schools and they want to know about, they want to know about my life.” She stated that she talked “(A)bout, um, [sniff], well I tell them about, all about me...What I do, um, where I work... Um...what I do, what I like to do for fun”.

Like her sense of pride and identity affirming feelings about her writing, Vicki spoke about the thank you notes from children, “(It) made me feel proud about myself. They like me”. Through her public speaking and writing activities, Vicki extended herself into the larger community and offered others an opportunity to learn about the lives of persons with intellectual disabilities.

Vicki’s religious value, which she stated simply as “I believe in God”, did not appear with regularity except for her direct discussion of religion. From the content analysis of her narrative it appeared that her strongest value revolved around the idea of respect; that everyone should be respected. On a personal level, she believed that to keep friends she “had to respect them”. She claimed another important value as believing in what you do.

Andy (age 43). A strong focus for Andy’s generative motivation and behavior centered on his relationship with his girlfriend and other friends. As he emphasized, he was several years older than his girlfriend and at times felt more like a father giving advice and caring for her than

as a romantic partner. He believed that "...I inspired Jackie" by living his belief that persons with disabilities should not give up. Included in his responses about his beliefs, Andy added that "(U)hm, I think the reason I'm doing this interview is that it's important to me to give a message to anybody, it doesn't matter if they are disabled or not. If they have a hard time in their life not to give up and to keep going".

Andy's narrative consistently echoed this theme of perseverance. Elsewhere he stated that:

I would say that it doesn't matter what kind of problem you have because everybody has problems. Try to be as happy as you can. Try not to let anything get in the way of that. Try to enjoy your life and try not to handicap yourself if you are labeled handicapped.

He expressed confidence that his actions reflected his values. His rule for life was, "just do what you know is right. And you know that you have to love yourself and love your family before you love anybody." Similarly, his single most important value in living was, "(T)o believe in yourself and to love yourself. And to not let anything get in the way of that". When asked about his congruence between these values and beliefs and his actual life, he stated, "I think that I did the right thing".

Andy shared that he discovered as an adolescent that he liked to make others, specifically girls, laugh. As he remembered:

That I always kind of liked it if I could make someone laugh. That always seemed to matter to me. To make, especially girls laugh because I felt like they would like me better if I had a sense of humor and they kind of could laugh. Because I helped them to relieve the stress we were dealing with.

Andy's ability to make others laugh offered him a connective/relationship opportunity as well as generative experience that perhaps he felt that he could not otherwise accomplish. The following comment offered such evidence:

I kind of connect myself with people, especially women, who feel lonely and alienated and they just want to laugh and something to make them feel like they're connected to someone.

Andy, who identified as a Democrat, believed that "...politics is important. I think that if you live in this country and you're a statistic, you should vote because your viewpoint matters." He also believed that "...Everybody has the right of their own

opinion and nobody has the right to hate somebody just 'cause they disagree". Andy did not specifically identify his religious beliefs as influencing his generative beliefs, values or actions.

Unlike other interviewees, Andy did not have a clear vision of his future. He stated that maybe he would marry, and "I'll just finally retire. I'll retire from working for the city and maybe I'll do some volunteer work and I'll probably have her (Jackie) in my life. But if I don't I'll find someone else...".

Ed (age 65). Discerning Ed's core values and generative themes posed a challenge due to his storytelling and tangential conversational style. However, specific content came to the surface for analysis. Two memories offered a glimpse of Ed's altruism and desire to contribute to the common good. Ed felt connected to the larger community primarily through his love of country music. He shared an experience in which he organized an autograph line for fellow music lovers to obtain autographs. For Ed, his effort indicated his loyalty and affection toward the musicians and by extension to country music in general. Ed also shared that for many years he dressed as Santa for participants of a senior program. As he recalled, "Oh God yes. People love me. I go to my clubs and play Santa Claus...to Senior Link...Everybody know who I was. ." Ed inherited this community-oriented responsibility, from

this guy who used to be um Santa Claus he pass the costume on to me, eh, so I love it...And then I was saying-I say let's have- let's have lunch with Santa Claus.... Lunch with singing and dancing...And they all loved the idea. They would sit on my lap, everything...I'd love it. I love it.

A consistent generativity theme of educating and caring for children appeared in many of Ed's stories and opinions. He declared that he hoped that in the future that, "I would like to come back is to help people out... I would like to help the kids to grow up you know. Some of the kids who's born, you know, don't know who their real mother and father is." Most likely referring to child abuse, he stated that he wanted to educate children about being "careful what relation they are, who they are where you meet them, what kind of family do they come from".

Ed's current behavior confirmed his future hopes as he shared his experience with helping a close friend raise her son. "...I took her over in 2000... Took over the father's responsibility of caring for him." This friend, also intellectually disabled, depended on Ed to help with expenses and babysitting responsibilities.

Ed echoed his generativity theme in answer to the question, "how would you finish, my life is?" to which he replied:

I would say my life is to help people out, to help the kids out who come into this world. Make sure you take care of your money, make sure your kids go to school, that the kids do their homework, make sure your kids to help around the house, to do your work, clean, and watch their mother and father what do you do with your life, you know.

Ed's beliefs originated from his strong fundamental religion that his "boss" was upstairs in Heaven. And that "(H)e tells me what to do in my heart. And he's the one that brought me down here on earth..." Although he did not talk at length about his political beliefs, he opined a view that reflected mistrust and pessimism toward government. He shared his concern about politicians taking away his government benefits and that future generations would not have Social Security.

Ed demonstrated his political awareness in local politics when he shared his thoughts about "a new gambling place" opening soon on the outskirts of the downtown area. He declared, "I don't like it because it's going to be too close to the welfare department and too close to the Salvation Army department." He did not approve of its location because

people are going to go gambling and they're going to have no money to go home with their family. What are we going to do now?...and then you do have the Justice Center down there, you know... And that's going to be too close to everything down there. ...And then you're going to go gambling, you know, how are you going to feed your family? Where is the money going to come from? It's going to come from the rich people. Or the poor people because money it's going to be hard to get a hold off because welfare ain't going to be around forever, social security won't be around forever.

In counterpoint to this feeling of powerlessness, Ed asserted his perceived power in the following statement: "We're the ones paying the taxes for the people. You and me, we are the Presidents...They're not our bosses, we are the bosses". However, his overall narrative carried a theme of powerlessness, resignation and fear rather than a confidence about his own power to influence. In this statement Ed reflected his pervasive sense of mistrust and pessimism: "I know, you gotta move on, when somebody has a life with a disability. ...We've got to learn who trust now a day. We don't know who to trust anymore. You've got to trust yourself."

Kevin (age 44). Analysis of generativity themes during Kevin's adult years revealed an individual who experienced a continual struggle to feel respected and positively recognized by his family, peers and the world at large. Kevin clearly saw himself as a survivor in this world and in a constant battle to maintain a positive attitude and to not succumb to "the streets". Wanting to distinguish himself from life around him, he stated that he "did not have that negative attitude...like gang banging". And that he wanted "everybody to 'get along'. That's what I did". However, Kevin understood that everyone did not always get along and therefore, "you just got to move on". Kevin expressed his self-awareness in his statement: "... "Uh, uh, life is simple; yeah, vote, uh, try to do the right thing, you. Try to help, you just be yourself that's all." Kevin wanted more in his life than merely surviving, he wanted to

Uh [pause], try to better my life, try to better it. That's only option, you know, 'cause if you don't try to better it then don't complain about it, you know, it's not going to help yourself to complain about it.

He appreciated that 'agency' people had provided him encouragement and actual help during his adult years and recognized that "(A) lot of people don't have that man". He took advantage of this help and made a better life for himself. In referring to how one lived one's life, he stated that actions "speaks for itself, speaks for itself..." and he considered it his responsibility to make the best of bad situations; to go beyond the negative.

Speaking from personal experiences of poverty, Kevin believed that one was responsible whether one remained in poverty. As he stated, "...cause, you're born poor, you ain't got to be poor...Cause you're born poor- because- cause you have bad times it ain't got to be like that". He continued that for those things that you can't understand, "that makes your lives miserable" you can make it "as long as you got the God with you...".

Kevin understood his challenges and found strategies to face them. He used the strategy of "helping them (older people) out doing things for them", thus staying away from peers and away from trouble. His earlier positive experience of living with and later caring for his grandmother prepared him for this self-preserving accommodation. Of added psychological benefit, this action brought him respect from others and a sense of being part of something larger than himself. In addition to helping the many seniors in his building, he volunteered for several years at a Meals on Wheels program, its primary population composed of elderly persons.

The complexity of race and class in American society did not escape Kevin's belief system. While Kevin espoused the belief of individual responsibility to achieve success, he also acknowledged society's double standard of those with money and those without money. An interesting observation was that he used the much publicized murder case of O.J. Simpson, an African-American sports star, to illustrate his point about class and power. In Kevin's worldview, he privileged class before race.

My point is that if he did it, you why he walk or why the poor guys do minor stuff, they go to jail but this guy kills or something you know, and he didn't go to jail for it, he didn't go to jail...You got money...anything possible.

On a personal experiential level, Kevin narrated many of his adult experiences through the lens of race and considered his generative spirit denied due to the prejudice/racism aimed at him. . He recounted:

helping this um white guy, Greg, I think, about four years ago...he was uh-he had cancer and um I stood by him. ... I would go to the store for him.... His girlfriend, she didn't like me at all and I couldn't understand why but um I dealt with it, you know, what I mean, you know, but honestly though I just can't understand why we stereotype. I mean because I never been in trouble in my life, you know. I don't gang bang, I don't, you know, bother nobody.

Despite this incident and the more frequent experience of white people crossing the street to avoid him, Kevin valued the idea of urban mixed neighborhoods and lived in such at the time of his interview. The value that he placed on living in a mixed neighborhood indicated his astuteness regarding the socio-cultural and economic community benefits of a mixed (racial and economic) neighborhood.

Kevin imagined himself as a photographer in his future scene. At the time of the interview, he had actively worked on this goal by completing a community photography course. Taking a broader sweep of his future, Kevin imagined being "surrounded by good people. When you're around good people you know, you know; make you feel good." And, in his own conversational style, he stated that he hoped to positively contribute to life. "It would be – it'd be a little bit of everything. So I'd be trying probably to – the good, try to get good part in there. That's the best time, I'd try to put all good in there."

Teri (age 35). Teri's spiritual beliefs grounded her generative motivation and behavior. Recovering from alcohol abuse, she believed that her life was saved, "through the Lord, um, I'm back on the right track... And because of that, you know, I am going to school".

Reflecting her strong spiritual sense and commitment to others, she offered the following story as her spiritual scene. Teri, late for work one day, waited on a bench for the city bus. A man sat next to her and started talking to her. As she remembered,

he was trying to get everything off of his chest...he was, um, trying to get back to his mom's house, but he had no bus fare. Um, he got kicked out of his apartment, evicted, um, he had no job; he did not know what to do. And he had no money to get on the bus to see his mom.... So, luckily, I had money. I gave money for his bus fare. I gave him a business card to the place where I was working, and said 'try that place. See if that works for you.' Um, I gave him a little extra money so he can get some lunch.

She continued, "OK. So we departed. Bus came and we went on our way. A few days later, I was at the WRC. This guy came by and said, 'I got the job. Thank you.'" Teri recalled how great she felt. She reflected on the spirituality of this meeting, believing that "(I)t was like the Lord was trying to put me there to help this guy. ...he (the Lord) used me to help."

Raised by Presbyterian ministers, Teri continued to practice her faith. When asked how her religion manifested itself in daily life, she shared, "Um, well, first of all He put me here. Um, and I know he put me here for reason, um, what the reason is, I don't know.... But I do know, I'm here because of Him". Teri also acknowledged that her life changed for the better with the help of a now close friend getting her "back on track" as well as "church people" who offered guidance.

In Teri's future story, she saw herself in a strong marriage, without children, and working as a social worker. Teri anticipated that she would complete school and become a social worker. In this future story she would feel "like I accomplished something". Based on her previous work with individuals with disabilities, she felt called upon to become a social worker and to help others. She related that:

because, for a simple fact, that, uh because of the simple fact that, I used to work with people, um, that... have more than one disability, maybe a mental disability as well as a physical disability, that kind of thing. Yeah. And I used to work with them, um, I used

to feed them, and that's when my heart just went out to them, and I did-, and when I figured out the social work part, um, that's when I decided to go for it, because, uh, that's where I feel like I need to be.

Teri narrated a consistent theme of social awareness and altruism when she discussed what she valued in life. She professed no specific values about politics, just that people "...should be treated respectfully. Um, treat them like you wanna be treated". In reflecting on her social values, she repeated that people deserve respect and added that she advocated for her home-mate, when she did not think that her home-mate was fairly treated. At a broader level, she advocated in her role as board member and speaker for the local Down Syndrome Association. Teri stated, "(L)ike I would go and speak in front of people about Down syndrome and my association, about myself". When asked what message she wanted to convey, she said, "(T)hat we are just like anybody else is. We are no different."

Teri denied that her beliefs or values had changed over time, but that she became a stronger advocate, "because of the negativity that my mother had on me". The exploration of Teri's life story revealed that she transformed this negativity into a redemptive story and produced a strong generativity theme.

Teri considered herself "unique" and believed that God had placed her on earth to do good. Acknowledging her struggle with alcohol, she identified herself as a "boomerang kid", and "prodigal son". In her own way, Teri claimed the negative parts of herself and then reframed her identity as having "a lot of potential" and as "a kid that learned a lesson". This level of maturity and self-awareness provided her motivation toward a more generative future. From her own response she described the major theme in her life as one filled with negativity due to drugs and drinking. However, she believed that the future looked, "...more positive than negative".

Rose (age 56). Rose's current role as a mentor to several female neighbors in her apartment building allowed her to act upon her strongly held beliefs about self-sufficiency. In this role she passed on valuable education and encouragement to the other women with intellectual disabilities regarding their skills and confidence about daily living, such as making change and budget shopping.

By Rose's account her parents inculcated this value early in her life. In her future scene she reiterated this life long striving for and success in self-sufficiency. "My future would look

good...Because I've-I've established it now myself... I've brought myself way up. Where I can do things for myself and manage my own money and that". Rose planned to continue to share her knowledge and experience with her neighbors. Rose also recounted a singular event in which she saved her neighbors. She remembered,

windows was flying everywhere and toilets and doors. And one of the older gentleman got his hand cut real bad... Everybody lost everything. I was the one that called Red Cross and got them to come down and place the ones that needed a place to live, to stay overnight."

This damage was a result of "...the sewer backed up cause it was raining so hard". Rose continued: "And if it hadn't been for me calling to see ...So I called CG&E and had all the electric and water turned off. If I hadn't the house would have blew up."

Rose's response to the question of what her actions said about her provided evidence regarding how she valued her independent thinking and capabilities. "It really gave me a lot of steam to do things. I knew exactly what I was doing and I thought quick and there was really no time to really think...."

Prior to her father's death, Rose assumed responsibility for decisions about her father's medical care, such as, using Hospice. At the time of the interview, Rose expressed concern about her mother's nursing home placement and Rose's inability to impact her mother's care. She wanted more involvement but felt stymied by her aunt's guardianship status for her mother's care.

In addition to her generative actions on a personal level, Rose expressed her altruism through her political efforts, such as working at the local polling stations and handing out political literature. She credited her father and grandmother with her Democratic Party allegiance and instilling this political motivation and behavior. As she recalled, "Grandma would always say, 'Them damned old Republicans don't do nothing, they just mess up the world.'" From her father, she valued voting as the way, "(T)o voice your opinion. And that's a very important thing especially now with society the way it is." In particular, Rose expressed concern for the economy and how "...people like me and senior citizens we're not going to be able to make it."

While Rose shared at length her experiences related to religious tensions in her family and her father's sobriety due to "being saved", she made no connection through her narratives or

in direct questions between her religious beliefs and her generative beliefs or actions. At the time of the interview, she related that her Catholic faith provided friendship connections. “Well, I have been going to the Catholic Church with my friends. I really value my friends over at the church. I really like it. I value them a lot but I – I’ve been so many things.”

Influential Experiences Related to the Formation of Identity

The life narrative offers a wealth of data that extends beyond the use of the concepts discussed above. For this research, a broader question was asked: Are there other contributing factors in the identity making process that are not described by communion, agency, generativity or stagnation? Included in the “other” category and discussed separately is the influence of disability on the identity making process. Demographic characteristics are contributing factors to the identity making process. In this research, these characteristics, which function as culturally imposed anchors to the identity making process, define who one is by race, religion and economic status. Both African-American interviewees (Kevin and Irene) shared memories infused with racial content, commonly marked with discrimination or prejudice. Three Caucasian interviewees (Otto, Ed and Marlene) included racial content in their interviews.

Influence of Racial issues and Racial Identification

Otto shared a memorable event related to the 1970’s urban riots that influenced his future value regarding respect for others and their property. He also shared that he frequently was the only white person on the city bus and that other passengers asked him why a white person rode the bus. As evidence of his awareness of racial differences in American society and his liberal values, Otto suggested that I interview his young African-American woman friend in order to ensure minority representation. Ed, who is close in age to Otto, recalled as his important childhood memory, the security and happiness that he felt in his racially mixed, poor neighborhood. As he remembered, “(W)e all walked to school together... We walked home from school... We had to hold hands or talk so that nobody could get out the car and say, “C’mon you’re going to go with us.”

Marlene, among the younger interviewees, related the distress she felt about a Klu Klux Klan rally in her small town. From this negative experience she opened up herself to exploring a meaningful relationship with an African-American young man. However, unlike Kevin’s and Irene’s stories, Otto’s, Ed’s and Marlene’s stories related more to values or singular events rather than intimate memories of identity making influence.

Religion

The importance of religion in the identity making process proved meaningful in many of the interviewees' narratives. Marlene and Teri considered their religious upbringing, as a Quaker and Presbyterian respectively, as central to their way of participating in their world, in terms of their generative values and actions. Alice, who as an adult was "saved", also lived her life as a devout Christian. Greg narrated the majority of redemptive themes as a result of divine intervention from drugs and suicide attempts. For Rose and to a lesser extent Andy, the activities related to formalized religion (ex. church attendance and missionary work) offered ways in which they could connect with their parents or friends. The Jewish faith appeared extensively in Rose's and Otto's narratives and contributed to their identity making process. Rose identified as the ostracized "other" in her Jewish grandmother's eyes. Jewish law prohibited Otto to fully claim himself as a Jew due to his disability. Throughout his life story, he reaffirmed not only his Jewish identity but also his identity as a resistance fighter for recognition within the faith.

Economic Status

The marker of economic status contributed to the identity making process in many of the interviewees' life stories. Those with lower economic status (Kevin and Greg) narrated stories and feelings that centered on their basic needs, whereas those raised in middle to upper-middle class families (Carl and Marlene) shared memories centered in nurturing their creativity and upward mobility.

Role of the Family

The intimate family experiences universal to all human development contributed to the identity making process. Apparent, as well, in the interviews were the family members' influence on the individual's process of identity. The individuals' narratives of these intimate experiences contextualized the interviewees' perceived role in the family.

For example, Marlene's childhood memories centered primarily on her role as a sibling, child or grandchild; not as a family member with a disability. Within her family, she felt loved and challenged to express her creativity, a characteristic valued by the family. As an adolescent, Marlene's self-awareness regarding her cognitive deficits came through academic challenges rather than through familial labeling of her deficits.

Teri's and Rose's life stories included a history of family dysfunction related to parental alcoholism. In her adolescence, Teri confronted her "differentness" and her mothers' consistent negative focus on her disability by joining a peer group of "normal kids who drank". Alice identified closely with her grandmother's psychic abilities. She also recognized that due to her intellectual disability, her grandmother did not guide her to use this paranormal gift. Otto and Ed evoked their mothers' spirit when talking about significant events in their lives.

Mentoring Relationships

Some of the interviewees considered the positive influence of nonfamily at transformative points as particularly meaningful. Specifically Teri, Otto and Alice described the mentoring relationship of others and how these relationships in adulthood changed the course of their lives toward a more generative and life satisfying direction.

Socio-cultural/historical Factors

On a larger contextual level, economic and political factors, and historical events at the national and local levels, contributed to the individuals' identity making processes. Several interviewees remembered, in their significant scenes, their 'place' in the community. For example, Ed remembered how important he felt within the larger community when he served as a batboy for one day for the city's professional baseball team. Also, his personal story of life in the 1960's and 1970's brought forth evidence of the impact of urban renewal/resettlement on a youth's sense of community attachment. Otto shared that he attempted to enlist in the military during the Viet Nam War and Carl shared his 'make believe' story of joining the army to fight terrorists. Marlene's involvement in a community youth sports league allowed her 'typical' developmental experiences of feeling competent and part of something larger than her. The terrorist events of September 11, 2001, the 1960's urban upheaval and the Vietnam War all played defining roles in adolescent and young adult development for several of the interviewees.

Examination of Themes by Scene

Turning Point Scenes

The turning point scenes, (redemptive and nonredemptive) offered support in understanding the meaningful impact related to socio-cultural transitional periods, such as moving from the family of origin to one's own space, obtaining a job, marriage and birth of a child. Moving from the family's home and to a home of one's own choosing marked not only a physical change but also a change in a social and personal identity. Likewise, moving from

financial dependency to more independency as a result of work marked not only an economic change, but also perhaps more importantly a socio-culturally recognized adult identity. Marriage and birth of child also created meaningful psychological and social identity markers. The redemptive turning point scenes highlighted the influence of the individual's affective and cognitive working model on the identity process. Redemptive themes found in the stories which focused on addiction and recovery highlighted the individual's resiliency; his or her ability to accept help and to internalize that support into a motivation for positive change. Often this help was foregrounded in religiosity and a belief that God had a unique plan for the person.

Low Point Scenes

As noted earlier, twelve individuals narrated 14 low point stories. Predictably and strikingly, one-half of the low point stories revolved around the death or critical illness of friends or family. Some individuals perceived this loss as an opportunity to positively live their lives in a manner that honored the loved one. They seized the redemptive quality of the experience and incorporated that memory into the making of their own identity, such as, an artist or a caring and good person. Other stories concerned the struggle and subsequent recovery from drug addiction, an interviewee losing her childhood carefreeness and taking on adult responsibilities, and an interviewee's battle with bedbug infestation. Except for two stories with disability content, these low point stories offered testimony to the challenges of typical human suffering.

High Point Scenes

Earlier, the 22 high point stories were explored for their agency and communion content. No one content theme emerged from the high point scenes. In order of frequency the following themes appeared, recognition of others, either formally or informally; feeling of closeness with family or friends; helping others; transitional events, such as moving away from family or buying a home; and starting work. As noted in the earlier agency and communion discussion, strong aspects related to a making of a social identity surfaced, i.e. the high frequency of high point stories told within the narrative of social recognition, particularly by institutions perceived as high status, such as the state Developmental Disability Council or Special Olympics.

Influence of Disability on the Formation of Identity

The influence of disability of the formation of identity was considered separately during data analysis of the scenes.

Examination of Themes by Scene

Turning point scenes. Three of the 11 individuals who narrated four turning point stories included themes related to their disability. However, the importance of the disability content within these stories was shared with the more typical content of transitionally related themes, such as moving from family of origin's home to one's own home and retirement. Of the four turning point scenes containing disability content, two also contained redemptive themes.

Low point scenes. Two of the low point stories contained content related to the interviewees' parents' reaction to the diagnosis of Down syndrome and the impact felt by the interviewee. Both stories were narrated from a position of redemption.

Teri's story directly related to her disability and specifically to her diagnosis of Down syndrome. She acknowledged that she was too young to remember this scene, however, as she explained, "I remember it being told to me." This family story began her self-identity as a person with a disability. She claimed this scene as her personal low point scene and internalized it into her overall story of redemption and identity making. Teri remembered the story that the pediatrician told her mother to "do what you can with this child... You can take her home and love her, but she'll never do anything...She'll never read or write."

Incorporated in this story was her parents' subsequent "deep depression", "when it was discovered that I was Down syndrome". As Teri (re)claimed this story, her mother defiantly reacted to this negative prognosis and declared, " 'Lady, you take care of her physically...' 'But I will take care of her mind.'" Despite this defiant stand, Teri took to heart that her parents "...took weeks for them to get out of it (the depression)." This story set the stage for a progressive life narrative of resistance or proving the doctor wrong; as indicated by Teri's proclamation, "look at me now" and that she attended college to become a social worker.

Vicki's low point story centered on her memory, at age 12, of her parents telling her for the first time about her diagnosis of Down syndrome. She recalled that she initially felt "kinda scary" to feeling happy because of her mother's reassurance "that I'm special". Affectively she gained a positive feeling about this difference. Cognitively and behaviorally her continued narrative reflected her positive identity as a person with Down syndrome.

High point scenes. Disability content is abundant in the high point stories. One-half of the individuals included disability content in their high point stories.

Two of the youngest interviewees (Carl and Marlene) narrated high point stories with strong disability content. For Carl and Marlene the high point of their lives centered on their involvement in programs supporting persons with disabilities. As Carl narrated, “(Organization’s name) is my life”, (Organization’s name) is great for me” In this story, Carl’s high point centered on his feelings of communion. His connection to this organization not only addressed his immediate friendships, but also spoke to a sense of belonging and of being part of something larger than him, “I’m part, I’m in it.”

Marlene identified her high point as “when I started at (Organization’s name), and then got a job at (School’s name)” (a private K-8 school that specialized in instruction for children with an autism spectrum disorder). She found tremendous satisfaction in this responsibility and narrated the story with communion subthemes of caring/help and unity/togetherness as well as agentic achievement and responsibility. This program offered Marlene an opportunity to develop and claim her identity as an artist and teacher; as she described this process, “at (Organization’s name) there’s actually a venue for this (making art) and I can actually say that ‘Oh, I’m gonna actually sell this piece of art.’ ” Selling her artwork legitimized her talent and self-identity as an artist. The experience of teaching children with autism, poignantly struck a chord for Marlene.

I got a job with Kim, um teaching kids with autism, um the highpoint was, um well, basically when I started, and I consider it as a highpoint as some of the people there I see in myself and it’s rewarding to teach art to different people. And I feel best when I can actually teach what I’m making money off of.”

Marlene began this identity making process as a child nurtured by her artistic and supportive family; now as a young adult, she continued this process through the procurement of work as an artist and teacher. Further enhancing her identity as a teacher with a disability was her sense of connection with the students, “(S)ome of the people there I see in myself”. Marlene’s self-insight echoed the group identity acknowledged by Alice and Otto. Rather than assuming the role of an advocate, which Alice and Otto chose, she channeled her generativity into teaching. For both Marlene and Carl, themes of communion occurred more frequently than themes of agency.

As attested by their high scores in agency in their high point scenes, Otto and Alice represented the older generative adults who claimed their identity as persons with a disability.

All six of Otto's high point scenes revolved around his identity as a person with a disability; two of Alice's three scenes did the same. Alice's stories reflected three times as many agency themes as communion scenes and 100% of Otto's themes were agentic.

For two other interviewees, Teri and Andy, disability also infused their high points. Teri narrated her high point as carrying the Olympic torch. In this scene, this young adult with Down syndrome, identified herself through the agentic lens of achievement and responsibility, status and victory as well as communion, specifically, love and friendship. Teri compared her feeling of importance to "when I was also picked to be a Board member at the Down Syndrome Association". When asked to describe this feeling she replied, "I felt very important".

Andy's two high points addressed the traditional adolescent to young adult socio-cultural markers of beginning work and starting a romantic relationship. For Andy, both high points became possible when he moved out of his parents' home and moved to a different city. He considered this period as a crucial identity-making period and aptly named his movie, "Find a Way Zone", with reference to the name of his apartment complex as well as acknowledgement of his personal identity quest. Andy perceived himself as resisting the socio-cultural stereotype of a "disabled son" living at home. As he described it, "...I was kind of weird because I did not want to live with my parents all my life." He continued, "(L)iving on my own is such a good thing and I just love this place". He stated that he tried to leave the building every day, to assert his "normalcy" as an active community citizen unlike others who lived in the building.

Upon living on his own, Andy began socializing with others with disabilities and met his girlfriend through this network. He described himself as a romantic and opined that

I feel like it doesn't matter who you are. If you're disabled or not disabled nobody wants to be alone. ...It doesn't matter what the disability. You're going to connect to this person if you feel and think the same way.

Andy found such a connection, "...with people, especially women, who feel lonely and alienated and they just want to laugh and something to make them feel like they're connected to someone." Andy's girlfriend, several years younger than him and described as having a mental illness, fit into this category of the alienated and lonely. He found an emotional connection with her as well as an outlet for his need to care for someone. This interdependency met his communion needs as well as agency needs in terms of assuming responsibility for someone other

than himself. As he explained she is kind of like "...my daughter and also kind of like my girlfriend. I help her along and then she helps me in certain ways..." .

Total Sample Findings

Overall Scoring of Loyola Generative Scale, the Generative Behavior Scale and the Satisfaction with Life Scale

Interviewees answered questions from three measurements: the Loyola Generative Scale (LGS), the Generative Behavior Checklist (GBC) and the Satisfaction with Life Scale (SWLS). (See Chapter 3 for descriptions of the measurements and Appendices B, C(B),D.) For comparison purposes, the Foley Center for the Study of Lives (www.sesp.northwestern.edu/foley/instruments/lgs/scorings) provided an average score of 40-41 for the LGS. Average scores for the GBC were not provided nor were average scores for the SWLS.

The overall findings for all interviewees were as follows:

1. On the LGS, one half of the interviewees scored average or above (average 40-41 points).
2. The LGS mean average for all interviewees (41.8) matched the Foley Center's LGS average (40-41). Interviewees' scores ranged from 27 to 60 points (60 possible points).
3. The mean average for all interviewees on the GBC was 29.6 points. Interviewees' scores ranged from 6-50 (80 possible points).
4. The mean average for all interviewees using the SWLS was 4.02 points (range 0-5). Scores ranged from 2.4 to 5 points.

Overall Scoring for Agency and Communion

During data analysis, scenes from the individual's life narrative interview were first coded into broad themes of agency and communion. Subthemes or categories within agency and communion were then coded. Possible subthemes for agency included, achievement and responsibility (A/R), Power and Impact (P/I), Self-Insight (S/I) and Status and Victory (S/V). Subthemes for communion included, Love and friendship (L/F), Dialogue (DG), Caring and help (C/H) and Unity and Togetherness (U/T). (See Appendix E Coding Systems for Themes of Agency and Communion.)

The average agency score per scene for the sample was .97 and 61.4% (N=148) of the scenes contained at least one agency subtheme. The average communion score per scene was

1.00 and 72.5% of the scenes (N=145) contained at least one communion subtheme. (One scene could contain both agency and communion themes.)

The four agency subthemes were distributed in the following proportions: Achievement/Responsibility: 49.4%; Power/Impact 17.2%, Self-insight 23.7% and Status/Victory 9.7%. (See Figure 4.1)

The four communion subthemes were distributed in the following manner: Love/Friendship 30.1%; Dialogue 15.4%, Caring/Help 31.7% and Unity/Togetherness 22.7% (See Figure 4.2)

Overall Scoring for Redemption and Contamination

As in the data analysis process for agency and communion, the interviewees' life stories were coded by scenes for evidence of redemption and contamination. (See Appendices F and G for Coding System for Redemption Sequences and Contamination Sequences). Of the total scenes (N=145), 26.2% were narrated with a redemption theme, while only 2.8% of the scenes were narrated with a contamination theme.

Group Compositions

Interviewees were divided into two groups, Group 1- Higher Generativity Group or Group 2- Lower Generativity Group. Members in Group 1 scored average or above average on the LGS and GBC. Members in Group 1 (Higher Generativity) included Carl, Greg, Alice, Irene, Marlene, Otto and Vicki. (See Table 4.2) Members in Group 2 scored below average on the LGS and GBC. Members included Andy, Ed, Kevin, Rose and Teri. (See Table 4.3)

Although Vicki and Irene (Group 1) did not meet the criterion of LGS of 42.5 or higher, they met the GBC criterion with a score of 40. I made the decision to include Vicki and Irene in Group 1 because they most fit this group's criteria. Vicki's and Irene's LGS scores of 40 and 39 respectively were closer to Group 1's average than Group 2's average. Group 2 members' scores were 36 points or less for LGS.

Group 1 members' scores for GBC were 31 points and higher which Vicki, with 40 points, and Irene, with 42 points, squarely fit in this group and Group 2 members' scores for the GBC were 21 points and less. Neither Vicki's nor Irene's story did not show any exceptional differences from others in Group 1 to warrant a stand alone outlier category.

Intergroup Findings

Demographic Characteristics of Group 1 and Group 2

As a group, Group 1 was slightly younger than Group 2, however, Group 1 included more individuals aged 46 years and older, a larger age range and the youngest interviewee. Overall men were slightly older than women in both groups. The average age for men was 50.8; average age for women was 44. The average age of men in Group 1 was 51; average age of women was 42.5. The average age of Group 2 men was 50.6, the women's average age was 45.5.

There were no differences between groups regarding racial composition; proportionately there were more women than men in Group 1 than Group 2. Both groups had a religious diversity; Group 1 members reported a slightly higher church/synagogue attendance routine than Group 2. Group 1 had a slightly higher proportion of those who were active in volunteer and/or paid work. Group 1 members were more involved in advocacy work than Group 2 members. More individuals in Group 2 lived alone in non-supported living situations. Group 1 had members who had children, Group 2 did not. (See Table 4.4)

Overall Scoring of LGS, GBC, and SWLS

As a group, Group 1's scores for each of the measurements (LGS, GBC, and SWLS) were higher than Group 2's scores. (See Table 4.5)

Overall Scoring for Agency and Communion

Group 1 scored higher in both the percentage of scenes that contained agentic themes and number of agency themes per scene. Comparing communion, Group 2 scored a higher percentage of scenes that contained communion and a higher number of communion themes per scene. (See Table 4.6)

Both groups narrated with the same frequency of agentic subthemes. Ranked from most to least frequent were: achievement/responsibility, self-insight, power/impact and status/victory. Group 1's stories contained a higher percentage of self-insight than Group 2. Group 2's stories were told with more achievement/responsibility and power/impact subthemes than Group 1. (See Table 4.9)

Findings, focused on agency and communion subthemes, yielded a similar ranking of subthemes between each group. However, there was a difference between the groups in terms of

the percentage of narration of subthemes (agency and communion) within the stories. In the area of agency, Group 1 used more self-insight and Group 2 used more achievement/ responsibility and power/impact. For communion, Group 1 narrated with a higher percentage of love/friendship, caring/help and unity/togetherness and Group 2 with a higher percentage of dialogue. (See Table 4.8)

Comparison findings from both groups to the total sample, yielded marginal differences. Comparing Group 1's agency and its subthemes with the total sample, Group 1 members scored close to the overall sample frequency of A/R. Group 2 members' more frequently narrated with the A/R subtheme than the total sample. Little difference appeared between the two groups and the overall sample for the subtheme of status and victory and power and impact. Group 1's self-insight scored higher than the total sample average and Group 2.

Agency and Communion Findings Related to Age

Analysis of agency and communion through the lens of age found that the subgroup of older adults (ages 46 and older) in the higher generativity group (Group 1) narrated their stories with higher percentages of agency and communion than their age peers in Group 2. The younger group of adults (ages 22 to 45) in the less generative group (Group 2) narrated their lives with a higher percentage of scenes containing agency and communion as well as more themes per scene than their age cohort in Group 1. There was no difference between the groups regarding the age at which the most agency or communion scenes occurred. The highest percentage of agency and communion themes occurred within the individuals' current age range.

Overall Scoring for Redemption and Contamination

Group 1 had a slightly higher percentage of redemption scenes than Group 2, 25.3% vs.22.4%. When comparing average redemption scores, Group 1 also produced a higher average redemption score (4.4) than Group 2 (3). The differences were accounted by additional points awarded for enhanced agency, communion and ultimate concern. In Group 1 nine additional points were scored, whereas Group 2 was awarded 2 points.

When comparing for narrative content for type of redemptive theme (growth, recovery, learning, and other improvement) the two groups were fairly evenly matched by percentage of redemption themes in the narrative content. (See Table 4.9)

Group 2 had a larger percentage of contamination stories (5.2%) than Group 1 (1.2%).

Intergroup and Intragroup Findings Related to Gender

Although the differences between men and women were not large, the differences that surfaced offer opportunities for further exploration.

LGS, GBC and SWLS. Overall Group 1 men reported the highest LGS and SWLS scores, higher than Group 2 members (men and women) and Group 1 women. Group 1 women scored the highest of all groups on the GBC. Group 2 women scored lowest on all scores (LGS, GBC, SWLS) than any other group. (See Table 4.10)

Scoring for agency and communion. Group 1 men had a slightly higher percentage of agency than Group 2 men. (See Table 4.10). Conversely, Group 2 men had a slightly higher percentage of communion than Group 1 men. Group 1 men had the lowest percentage of communion scenes than all other groups. Similar to the males, Group 2 women had a higher percentage of communion than Group 1 women. Group 2 women had the highest percentage of communion scenes than all other groups. (See Table 4.10)

In each group women narrated their stories more frequently with agency and communion scenes than did men. Women also had a higher score per scene in both agency and communion than men. Group 2 women had the highest percentage of agency than any other group, male or female. Group 2 men had the lowest percentage of agency than any other group.

Scoring for redemption and contamination. In the area of redemption and contamination, women's stories on average had a higher percentage of redemptive themes than men's stories (32.3% vs. 23.5%). Group 1 men had a slightly higher percentage of redemption stories than Group 2 men. The opposite was true for women, Group 2 women had a higher percentage of redemption stories than Group 1 women and men in both groups. Group 2 men had the lowest percentage of redemptive themes in their narratives. While neither Group 1 men nor women narrated contamination themes, both genders in Group 2 had such life stories. However, there were too few contamination stories for comparison purposes.

Intragroup Findings

Higher Generativity Group - Group 1

Agency and communion. Within each group various demographic indicators were matched with the individuals' agency and communion results. While age did not account for differences between the members' scores, gender differences did appear, regarding agency and communion themes. Women narrated their lives with a higher percentage of scenes containing

agency (71%) than did men (57%). Women also had a higher percentage of scenes with communion themes (77%) than their male counterparts (65%) and more communion themes per scene (1.1) than the men (.66).

In considering the communion and agency subthemes, Alice, the most agentic and communal narrating individual, told her stories through the underlying self-insight subtheme (32%). The others narrated their stories employing the achievement and responsibility subtheme. (Irene was equally as likely to narrate through A/R as she was S/I.).

Members narrated their stories least frequently using a status/victory subtheme (9.8%). The youngest group member, Carl, scored the lowest percentage of agency scenes and most frequently told those agentic scenes using status/victory statements (25%) compared to other group members. Two individuals (Irene and Greg) had no agency stories containing the status/victory subtheme.

In Group 1, the average agency score (.89) of the two youngest members (Carl and Marlene) was almost one-half the agency score (1.9) of the two oldest members (Otto and Alice). Age did not add to the understanding of the type of and frequency of agency subthemes. However, there were gender differences. When comparing men and women regarding agency subthemes, women more often narrated their stories with self-insight into their own agency. Every woman and one man narrated using at least one agency subtheme of insight.

In the area of communion subthemes, women narrated their stories with considerably more dialogue and unity/togetherness than men. No man narrated his story with a dialogue subtheme. Men and women had similar frequency of narrating their stories using the subthemes of love/friendship and caring and help.

Another potentially meaningful indication of agency and communion is religious activity. There were no differences in agency and communion scores found between those who declared themselves as church members as those who did not. However, upon exploration of the subthemes within the agency and communion stories one difference was found. Two of the four church goers (Marlene and Vicki) narrated their communion stories most often with the subtheme of unity/togetherness, while none of the non-church goers did so. Often Marlene narrated her stories within the framework of her Quaker identity. She embraced the openness of the Quakers, "...really what the Quakers seem to do is like, they look past like barriers....The barriers would be skin color, different religion, um, or like, or like different, um background."

This openness extended to an eagerness to explore and understand persons who were of a different religion or race. As noted in a previous section, Marlene's self-awareness and value of understanding others took forefront in her desire for communal dialogue following the terrorist attacks of September 11, 2001.

Vicki's unity and togetherness subthemes more often reflected her positive family experiences as well as her religious beliefs. Many of her childhood and adolescent memories were remembered as "just hanging out with my friends" and feeling good about this sense of togetherness. Her religious memories concerned her sense of unity with her family in addition to her connection to God. There was a social/communion element to her religious identification, as Vicki described how she celebrates the holidays, "(H)anging out with my friend." For Vicki being Catholic also meant that she can "let God know that I am, um, Oh, come on, to let God, yeah, I, to think about him." For clarification, the interviewer, repeated the answer, "So it's important to be Catholic because it lets you think about God?" Vicki answered, "Yeah." Vicki returned to the celebration of Lent stating that she celebrated Lent because "... (I)t's like celebrating God."

Relationship between agency and communion and LGS, GBC and SWLS. Alice had the highest percentage of both agency and communion themed scenes. She scored the second highest LGS (58), the highest GBC (50) and was one of three with the highest SWLS (5). She exemplified the assumed persona of an individual who was rich in qualitative stories of agency and communion and whose quantitative scores corroborated this narrative richness. The other group members' scores did not as easily fit this persona, but reflected a mix of high and low quantitative scores when considered with the agency scores. When considering the communion scores, members' results from the LGS, GBC and SWLS had a more compatible fit. For example, two individuals (Marlene and Otto) with the lowest percentage of scenes with communion also scored low on the GBC and SWLS. Another individual (Greg) who scored below the group average on the communion score per scene (.65) also scored below the group's average on the SWLS, LGS and GBC. Irene who scored low in terms of points per scene in communion scored low on the SWLS.

Relationship between redemption and contamination and LGS, GBC, and SWLS. Within Group 1, a connection existed between redemptive stories and scores from the three quantitative instruments. On average, one quarter of the group's narrated scenes included a

redemptive scene and one individual narrated a contaminated scene. Six of the seven members narrated at least one redemption scene. Those with the three highest percentages of redemption scenes (Greg, Alice, Marlene) achieved a higher average SWLS score (4.7) compared to the four with the lowest percentage of redemption scenes (av.3.6 SWLS). No clear pattern was discerned regarding those individuals with high redemptive scores and frequency of agency and communion subthemes. However, Greg and Alice who scored high in percentage of redemption scenes also scored high on the LGS, GBC and SWLS. Carl who was the other individual who received the maximum 5 on the SWLS scored relatively high on the LGS and GBC but had no redemption scenes. That Greg and Alice are two of the oldest members and also among the most religiously influenced members may contribute to the high percentage of stories perceived as redemptive.

The subgroup with higher frequency of redemptive stories (Alice, Greg, Marlene) narrated with more growth, recovery and learning content than did the lower frequency group (Otto, Vicki, Irene, Carl). This last group's narrative contained more themes of improvement.

Lower Generativity Group- Group 2

Agency and communion. In considering age when exploring the concept of agency and communion, Ed, the oldest group member, had the lowest percentage of scenes with agency and the smallest average of agency themes per scene. Teri, the youngest member of the group had the highest percentage of scenes with agency and the highest average of agency themes per scene. In considering gender and its relationship to agency and communion, women expressed their stories with a richer sense of individuation and communion. The women averaged two times more agency (75%) than the men (47%) in the total number of scenes. In the communion area, the women also narrated their lives with higher percentage of scenes containing communion (80%) than did men (70%).

Further analysis included review of communion and agency subthemes. All group members most frequently narrated an achievement and responsibility sub-themed agency story; and most frequently narrated a caring and help communion subtheme. Kevin's narrative was the highest within the group for achievement and responsibility (71%). Three individuals (Andy, Kevin, Rose) narrated no scenes with the status and victory subtheme. Within the group, Ed scored highest on the status and victory subtheme (40%). Status and victory was the least

communicated agency subtheme (9.6%). Unlike the predominance of achievement and responsibility in the agency category, there was no predominant communion subcategory.

When considering gender differences, men more frequently narrated subthemes of power and impact, than women, (30% vs. 11.3%), and status and victory (13% vs.4%). Women more often narrated than men using the self-insight subtheme (22% vs.19%) and achievement and responsibility (44% vs. 37%). Only Ed narrated no scenes with self-insight and Kevin narrated no scenes with power and impact. Men and women showed little difference in the communion subthemes.

When considering religious activity and agency and communion, meaningful differences in agency scores are evident. The average agency score for those with regular church attendance (Rose, Andy and Teri) was 72%, and those not with regular attendance was 38%. There was little difference in communion themes between those with regular attendance and those without regular attendance.

Looking at the subthemes of communion, those with religious activity scored more than twice the percentage of scenes with the subtheme of love/friendship than those who did not participate regularly in religious activity. Rose considered herself surrounded by friends at her supervised apartment building and attended parish functions with them. Andy felt close to many friends and felt an allegiance to those who were lonely and shy. Teri stated that she had a few close friends who gave her much support to stay sober. She also identified herself as “saved” and believed that her purpose was to do “God’s work”. Those who did not identify themselves as active church goers, Kevin and Ed, narrated few stories which involved love and friendship. While Ed’s early stories contained love and friendship his later stories did not. Kevin narrated only one story with a theme of love and friendship. Rather than love and friendship, Kevin’s and Ed’s communion themes contained subthemes of caring/help and unity and togetherness. These subthemes were evidenced in their family focused narration rather than friendship centered stories.

Relationship between agency and communion and LGS, GBC, and SWLS. No pattern was found between the subthemes for agency and communion and LGS, GBC, and SWLS.

Relationship between redemption and contamination and LGS, GBC, and SWLS.

No discernible pattern between SWLS, GBC, and LGS and redemption was discovered in Group 2. There were too few contamination stories for comparison purposes.

Relationship between agency and communion and redemption. Kevin and Teri, who had the highest scores in agency and communion, also scored the highest percentage of redemption stories. As described earlier, Teri narrated many of her life scenes through the lens of recovery. Her family history reflected a paternal struggle with alcoholism and resultant family dysfunction. As an adolescent, Teri abused alcohol and as a young adult struggled in recovery. Her remembered past focused on her destructive attempts to fit into a nondisabled peer group who drank and used drugs. “I was rebelling against myself- I didn’t want to be different and I was told that I was different (from family and friends) by mother.” She held her mother as the figure that continually made her feel different, less important than others in her world.

Teri’s psychological journey was constant growth, but not without setbacks. She described herself as the “boomerang kid” and the “prodigal son”, when referencing her independent living and movement toward individuation. Teri was also the only group member actively involved in advocacy work. She had reclaimed her identity as a person with Down syndrome and placed great value on recognition of her personal achievements. She described herself as “important” and “worthwhile”. She considered that God “put me here for reason, um, what that reason is, I don’t know”.

Kevin narrated his life story through the experiences of an impoverished African-American man who lived a life full of challenges to “survive”. He credited his grandmother’s love and guidance throughout his childhood and adolescent years with keeping him “out of the streets” and away from trouble. He reciprocated his grandmother’s dedication by caring for her after her cancer diagnosis. His narration of these memories carried deep themes of both agency and communion. His stories were the highest in Group 2 for achievement and responsibility. Kevin found redemption in his struggles with family and poverty. Indicative of his redemptive spirit Kevin declared that he had “...hope, hope, hope. Not luck, hope...”.

Between Group Comparisons

Redemption and contamination findings. Differences between the Higher and Lower Generativity Groups regarding redemption and contamination themes were explored in the turning point and low point scenes.

Turning point scenes. The turning point scenes from each group were explored for patterns of redemption. Group 2-Lower Generativity narrated a higher percentage of redemptive turning point scenes than Group 1 –Higher Generativity. Group 1’s redemptive scenes contained more religious content than Group 2. The majority of Group 1’s redemptive content included the psychological growth subtheme; one person narrated with a recovery subtheme. In Group 2, the content of the redemptive stories varied from recovery, psychological growth and learning.

Low point scenes. In Group 1, 57% of the low point scenes were narrated with a redemptive theme, two of those stories revolved around the positive psychological growth following the death of a significant person. In Group 2, 80% of the scenes were narrated with a redemptive theme, with one of those scenes centered on the positive psychological growth following the death of a family member.

Three-fourths of the low point narratives were redemptive in content. In both groups an individual narrated her low point around the diagnosis of Down syndrome and both were redemptive stories. The Group 1 individual found redemption in the story due to the love and reassurance from her parents that she was special. The Group 2 individual perceived the mother’s determination to prove the doctor’s wrong regarding a poor prognosis as redemptive. She considered her present life as meaningful and full of promise. Each group also included an individual who narrated the low point scene as a redemptive experience related to alcoholism or drugs.

Agency and communion Findings. Comparisons of the turning point, high point, low point, earliest childhood, wisdom and future scenes between the Higher and Lower Generativity Groups produced insights regarding differences in agency and communion between the groups.

Turning point scenes. When comparing the agency themes between groups, the majority of members in each group narrated at least one scene with self-insight. The evidence of self-insight in at least one agency narrative for each person confirms that interviewees understood the definition of turning point. One woman in each group narrated with a power and impact subtheme. The most frequently narrated subtheme for each group was self-insight followed by achievement and responsibility.

Regarding communion, no interviewee in either group narrated from a perspective of unity and togetherness in the turning point scene. In Group 1-Higher Generativity the subtheme of love and friendship ranked first in frequency followed by caring and help. In Group 2-Lower

Generativity the most frequently narrated subtheme was caring and help, followed by love and friendship.

High point scenes. Investigation of agency in the high point scenes found that a smaller percentage of Group 1- Higher Generativity members narrated their scenes using agency than Group 2-Lower Generativity. However, when comparing the frequency of agency subthemes per scene, Group 1 members narrated more subthemes per scene than Group 2; i.e. the intensity of agency was richer in Group 1 scenes than Group 2. The most frequently narrated subtheme was achievement and responsibility for both groups. In Group 1, two persons (Otto and Alice) narrated with the subthemes of power and impact and status and victory. Only Alice (Group 1 member) narrated with the insight subtheme. In group 2, two of the five (40%) (Teri and Ed) narrated with a status and victory subtheme. The analysis of the four status and victory narratives, taken from Group 1 and Group 2, revealed that disability related content was central to three of those stories (75%).

In analysis for communion themes, the majority of Group 1 (86%) narrated from a communion voice, with love and friendship as the most frequent communion subtheme. Group 1's narratives contained more agency themes than communion themes; contrasted with Group 2's narratives in which communion themes were more common than agency themes.

All Group 2 members narrated their high point with at least one communion subtheme. Group 2 members also narrated more frequently with the unity and togetherness subtheme than Group 1. No member narrated with a dialogue subtheme; whereas two people in Group 1 narrated with this subtheme.

Low point scenes. The majority (71%) of Group 1's low point scenes centered on the individual's experiences with death, in contrast to the Group 2's stories (40%) related to this life experience. The analysis of Group 1 stories for patterns agency and communion found that four of the seven (57%) low points stories contained agency. Achievement and responsibility was the most frequent subtheme in the agentic stories. Six of the seven (86%) of the stories contained a communion theme. The narratives included all subthemes, with love and friendship narrated most frequently.

In Group 2, three of five individuals (60%) had themes of agency in their stories, Similarly, three of five had communion themes in their stories. Each agentic story contained a subtheme of achievement and responsibility. Other subthemes included power and impact and

self-insight. Unlike Group 1, love and friendship was not narrated but rather dialogue, caring and help, unity and togetherness.

Earliest childhood scenes. Differences in agency themes between groups appeared in the analysis of the earliest childhood memories. Three Group-Higher Generativity members narrated with at least one agency theme, while agency was not present in any Group 2-Lower Generativity narrative. The agency subthemes present in the Group 1 narratives were self-insight and agency and responsibility. The majority of both groups remembered their earliest memories in rich communion detail. Unlike Group 2 stories, Group 1 stories did not contain a love and friendship subtheme.

Wisdom scenes. All Group 1-Higher Generativity members provided a wisdom scene, while only three Group 2-Lower Generativity members provided such a scene. Group 1 members (except for Greg) narrated their wisdom scenes from a strong agentic voice; with all but, Greg, narrating at least one agency subtheme per scene. The subtheme of power and impact was most evident in this scene than any other analyzed scenes. Group 1 members narrated no scenes with status and victory, with the subthemes shared between power and impact, self-insight and achievement and responsibility. For the three wisdom scenes narrated in Group 2, each scene contained at least one agency subtheme with achievement and responsibility most frequent. No Group 2 wisdom scene carried a power and impact subtheme or status and victory subtheme.

In Group 1, the communion narrative was richer in subtheme content than the agency theme, as evidenced by the equal number of agency and communion themes but with fewer individuals who narrated with communion. For example, Alice narrated her wisdom scene with all communion subthemes (4) and Otto narrated with dialogue and caring and help subthemes.

Group 2's wisdom stories did not contain the richness of communion subthemes evident in Group 1. For both groups the caring and help subtheme was most often narrated.

Future scenes. In general, Group 2-Lower Generativity individuals did not anticipate their future with the detail and certainty of those in Group 1-Higher Generativity. In Group 1, one person (Otto) did not share a future scene. Of the six who shared their future vision, the majority narrated more from an agency rather than a communion perspective. In contrast to Group 1, Group 2 stories contained more than twice as many communion themes than agency themes. Only two of the five in Group 2 narrated with an agency theme while only two of the

six Group 1 members narrated with a communion theme. Achievement and responsibility was the primary agency subtheme for both groups. There was no prevalent communion subtheme in either group.

Generativity and stagnation findings. Members in Group 1-Higher Generativity participated in the larger community at a more authentically engaged level and with more frequency than Group 2-Lower Generativity members. Arenas for active involvement included church activities (ex. missionary work, church attendance); volunteer or paid work, and advocacy work (ex. homeless and disability). While many of these activities occurred during the adult years, they served to validate the individual's identity as a contributing citizen. Participatory citizenship encouraged a sense of being part of something greater than themselves, i.e. generativity, and provided opportunities to exert individual agency.

While not directly addressing the individual's experiences, it is noteworthy that the only agency subcategory in which there was a noticeable difference between groups was in self-insight; on average Group 1 more frequently narrated their agency scenes (27%) with self-insight than Group 2 (20%). This finding suggests a possible connection between higher generativity and possessing the self-insight to interpret one's personal meaning of agency.

As a group, Group 1's scores for each of the LGS and GBC and SWLS measurements were higher than Group 2's scores. When comparing men and women, Group 1 men scored higher on the GBC, LGS and SWLS than their Group 2 male peers. Men in Group 1 scored the highest SWLS score of any group. For women, the greatest differences occurred in the GBC and SWLS scores. Group 1 women scored the highest of all groups (Group 1 and 2 males and Group 2 females) on the GBC. Group 2 women had the lowest average GBC of all gender groups (Group 1 and 2 males and Group 1 females). Group 2 men's GBC scores were 18 compared to Group 2 women's scores of 8.5. The average combined score for men (Group 1 and 2) was higher on all instruments than women. Group 2 women scored lowest on all the quantitative instruments (GBC, LGS, SWLS) than any other group.

Influential experiences related to the formation of identity. Key demographics, such as age and religion, offer a lens for comparison between Group 1- Higher Generativity and Group 2- Lower Generativity. There was not a large enough racial mix in the sample to compare between groups. Each group included one African American individual.

Religion. Four of seven (Marlene, Alice, Greg, Vicki) Group 1- Higher Generativity- members considered themselves religious, compared to four of five (Teri, Andy, Rose and Ed) Group 2- Lower Generativity. However, there is a qualitative difference of religious values, beliefs and actions between Group 1 and Group 2 members. Marlene, Alice and Greg ‘lived their religion’, in their generative actions. While Otto did not consider himself religious, His Jewish religion provided significant opportunities for his generative motivation. In Group 2, Teri was the only member who consistently tied her religious beliefs to her day-to-day actions.

Economic Markers. Both groups included individuals from impoverished to middle class backgrounds, no intergroup differences were discerned.

Gender. Gender did not influence the membership of either the lower or higher generativity group. There was not a positive pattern regarding gender and agency and communion in terms of placement in either group.

In terms of gender differences between the two groups in the narration of redemption and contamination stories, Group 1 men had a slightly higher percentage of redemption stories than Group 2 men. The opposite was true for women, Group 2 women had a higher percentage of redemption stories than Group 1 women and men in both groups. Group 2 men had the lowest percentage of redemptive themes in their narratives. However, it is noted that many of Group 2 women’s stories were related to alcoholism, which may have more of an impact on the identity making process than gender.

Age. As reported earlier, the stories of Group 1-High Generativity members, aged 46 years and older, yielded a higher percentage of agency and communion themes than their Group 2-Lower Generativity age peers. The opposite was true for the younger subgroup, i.e. Group 2 members, aged 22-45 years, narrated their stories with more agency and communion themes than their age peers in Group 1.

Role of family. Although the interview questions did not directly address the role of the family, a tentative generalization can be made as a result of content analysis of the overall life stories. Members of Group 1- Higher Generativity narrated more positive stories about their families of origin than did Group 2- Lower Generativity members. In Group 1, Marlene shared stories of the positive influence of her grandparents, and her parents’ efforts to involve her in community activities. Alice, while vague about her early childhood, spoke positively about the consistent support she felt from her sisters and their children. Vicki’s source of comfort and pride

came primarily from her relationship with her parents and siblings. Carl's childhood memories revolved around the happy times with his family at sport events. Otto's life story was threaded with his mother's love for him and his brother. Irene's and Greg's stories are less positive. Irene remembers her best family times during her early childhood years. Family dysfunction began with her parents' divorce, when she was young and continued throughout her pre-adult life. As a teen, Irene assumed major caretaking responsibility for her terminally ill sister as a teenager. Irene struggled with the need to feel loved by her mother, who treated her as an incompetent child. Irene imagined the title of her movie as *How to get along with your parent-mother*. Greg, who was homeless and parentless at an early age, marked his life story as one of loneliness and fear until he was saved by God.

Several members of Group 2-Lower Generativity- connected their experiences in a dysfunctional family to who they had become today. Teri's father's alcoholism negatively influenced her childhood years. In her adolescent years, conflict with her mother significantly influenced her life path, which included failed living situations and a battle with alcoholism.

A father's alcoholism also negatively impacted Rose's early life, as she described fights between her mother and father related to his alcoholism and out of marriage relationships. Additionally, her paternal grandmother's disclaimer of Rose, due to a mixed religious marriage, added to the psychological insecurity within her family of origin.

Although raised by a caring grandmother, Kevin recounted an absent parental-child relationship. Kevin shared the negative experience of his family's accusations of his possible drug use; he felt disrespected and angry toward them.

When talking about his parents, Andy perceived himself as an outsider in his family due to his cognitive disabilities. With a palpable sense of loneliness, he recounted his father's difficulty to relate to him. He felt further psychological injury due to his parents' and younger sister's (future) legal hold on him, regarding guardianship.

Ed's narrative contained the most consistently positive family memories. He shared fond memories of childhood with his family, feeling a part of the community, memories of travelling with his mother as an adult, and positive memories of his deceased sister.

Role of friends. Group 1 individuals had a broader friendship network and more ties to people in the broader community than Group 2. Six of seven Higher Generativity members actively participated in community oriented groups, ranging from advocacy work to teaching art

or participating in a writing group, to attending AA meetings. A theme of meaningful friendships and ties to the larger community evolved from their narratives. Their generative activities, which involved broader social commitments, placed them in a consistently self-reinforcing environment for continued generativity and positive identity making. In Group 2, only two of the five (Teri and Andy) were active in community-oriented groups, thus involved in broader social networks. Two of the five individuals, (Ed and Rose) narrated stories of strong extra-familial relationships, however, these were limited to a smaller network of friends from work or the apartment complex.

Socio-cultural/historical factors. Differences in story content associated with socio-cultural and historical events occurred between Group 1 and Group 2. Those with higher generativity more often narrated personally meaningful memories within the context of socio-cultural, political or historical delineators than those with lower generativity. Group 1's life stories bore witness to their psychological presence in the world around them. For example, in Group 1, Marlene, among the youngest of the interviewees, talked about the life changing tragedy of the World Trade Center plane crash in terms of her "quest for learning" about people different from her. For Marlene, this marked a significant life changing generational event. This story matched the emotional and moral content of her two earlier stories, one involving the presence of the Ku Klux Klan in her suburb, "to scare off black people", and a second story about her romantic involvement with a African-American peer, which "really... opened me up, um, really there's something behind the skin of everybody". Marlene's internalized Quaker values directed her psychological response within this historical time. As a Quaker, she reframed the events of September 11th into a quest of ultimate concern and a call for her moral responsibility to humanity. Experienced as a redemptive story, this socio/cultural/historical transformative event provided her an entrance into the larger moral world of ultimate concern.

Carl narrated his life story from an American male adolescent perspective. His patriotic desire to "be a soldier, army soldier...fighting in Iraq", located his psychological place in the current historical and political moment. Carl's idealized self, told through his imagined scenes, matched other adolescents' dreams of fame and external recognition. Carl lived out this masculine myth by volunteering with local military support that mailed packages to soldiers.

Otto's life story serves as the final example of the depth of Group 1's lived experience in the socio-cultural world. Otto, a verbose storyteller, narrated many of his identity making

memories through the fabric of the historical moment. He imbued his life story not only with the burgeoning advocacy efforts of parents of the 1950's but also with meaningful reference to the Vietnam War and the racial tensions in his neighborhood, which reflected the overall American crisis. Claiming his patriotism, he recalled that he attempted to enlist at a recruiting office only to be turned away due to his disability. He reflected his feeling "that hurt, I'd have love to done that".

In contrast to Group 1, Group 2 members did not tell the majority of their stories through a historical or socio-cultural lens. Kevin's life story and to some extent Ed's story, stands out as an exception. Kevin clearly articulated the impact of socio-cultural influences and expectation on his identity making process. As an African-American man living in the central city of a mid-size urban area, he experienced poverty, prejudice and a feeling of constant peer pressure, "to live on the streets". Whereas, young White middle class men, such as Carl, typically strived to successfully achieve the same dream as their socio-cultural peers, Kevin actively resisted the peer pressure but rather sought his family's positive regard and respect of professionals, such as educators, clergy and case managers. Ed's stories of his early childhood evoked a melancholy for a racially diverse neighborhood, in which children, black and white, played together and the streets were safe for everyone. This remembered idyllic life was disrupted by the geo-political resettlement of poor people in urban neighborhoods. While remembering his past in this manner his present evidenced no advocacy related to racial tension or economic disparity.

Influence of disability on the formation of identity. The influence of disability in the life experiences and thus the identity making process of Group 1 and Group 2 members is evident. For Group 1 members, much of their generative activities took place within the auspices of disability-centered organizations. While some Group 2 members were involved in disability agency sponsored programs, they did not primarily identify their generative activities within the scope of those organizations.

Of the 12 interviews, seven identified as advocates. Six of those seven were in Group 1-Higher Generativity. All but one of the seven identified as advocates for persons with disabilities. One identified as an advocate for persons who were homeless. Teri was the advocate in Group 2. Teri's story is marked with strong themes of family dysfunction, alcoholism and a difficult recovery. Placement in Group 2 reflected her scoring on the criteria

established for group selection. As noted below she scored lower on the quantitative instruments than the other six advocates.

Examination of Themes by Scene.

Turning point scenes. Exploration of the turning points scenes revealed one scene narrated by a Group 1-Higher Generativity young woman who was recognized by the local Developmental Disability Services agency for her success in gaining independence. She narrated this scene with self-insight, and status and victory. There was no overt disability related content by Group 2 members in the turning point scenes.

High point scenes. In the combined high point scenes for Group 1-Higher Generativity and Group 2-Lower Generativity, three of the four status/victory agency themed narratives contained disability related content. More of Group 1's high point scenes contained themes of success and recognition which revolved around disability related experiences than Group 2 stories.

For Group 1, these disability-related experiences were narrated with more agency and contained the agency subthemes of achievement and responsibility, power and impact and status and victory. Group 2's experiences carried a stronger pattern of communion themes.

Low point scenes. In the low point scenes, each group included one member (both whom identified themselves with the diagnosis of Down syndrome) who narrated a disability content focused scene. Both scenes were also redemptive.

Earliest childhood scenes. In the earliest childhood scenes, two Group 1 members (Alice and Otto) included a disability-centered narrative. Only Group 1 included disability centered earliest memories, both stories contained a redemptive theme.

Wisdom scenes. In Group 1, two of the seven wisdom scenes contained disability-focused content. No Group 2 members included this content in their wisdom scene. Alice's scene consistently fit with her overall life theme of recognizing and using her own power, translated in this scene as wisdom, to empower other persons with disabilities. Otto's wisdom scene, also consistent with his overall narrative, centered on his advocacy for self-determination for adult children with intellectual disabilities and their families. The remaining five scenes related to either decisions which involved the care and help of others (not disability focused) or introspection and subsequent change in one's self-perception or behavior. No Group

2 narrative contained a disability theme. Two of three scenes were primarily focused on self-awareness. The third scene involved helping another person.

Future scenes. Only Alice's (Group 1) future story contained specific disability themed content. Most of the remaining stories in both groups centered on family or career, or helping others (non-disabled). One Group 1 member (Marlene) envisioned a future focused on personal goals centered on greater independence in addition to career goals.

Summary

Twelve individuals with mild intellectual disability were interviewed using the life story interview and three quantitative instruments. Based on the scores from the Generative Behavior Scale and the Loyola Generativity Scale interviewees were placed either in Higher Generativity Group or Lower Generativity Group. Data analysis occurred on three levels, individual case, between group and within group. Findings were reported using the topics of agency and communion, redemption and contamination and generativity and stagnation. The influence of disability was explored in addition to other identity making influences, such as race, religion, economical status, role of family, mentoring relationships and socio/cultural influences. Table 4.113 presents the major findings described in Chapter 4.

Table 4.1 Comparison of Interviewees' Agency and Communion Themes, Agency and Communion Subthemes, Percentage of Redemption

	LG S	GBC C	SL WS	Agency Themes per Scene	Communion Themes per Scene	*Most Frequent Agency Subtheme	*Most Frequent Communion Subtheme	% of Redemption Scenes per Total Scenes	% of Contaminatio n Scenes per Total Scenes
Total Sample	41.8	29.6	4.02	.97	1.00	Achievement Responsibility 49.4%	Caring/Hel p 30.8%	24.1% (35) (N=145)	2.8% (4) (N=145)
Interviewee's Name									
Carl Duggin	57	42	5	.57	.71	Achievement Responsibility 50%	Love Friendship 60%	0	0
Irene Jacobs	40	42	2.2	.92	.90	Achievement Responsibility 44%	Love Friendship 44%	10% (1)	0
Greg Hill	60	41	5	.64	.64	Achievement Responsibility 44%	Caring/Hel p 85.7%	50% (5)	10% (1)
Alice	58	50	5	1.86	1.75	Self-Insight 32%	Love	28.6% (4)	0

Table 4.1 (continued)

	LG S	GBC C	SL WS	Agenc y Theme s per Scene	Communio n Themes per Scene	*Most Frequent Agency Subtheme	*Most Frequent Communio n Subtheme	% of Redemptio n Scenes per Total Scenes	% of Contaminatio n Scenes per Total Scenes
Baker							Friendship 35%		
Marlene Newcom b	48	38	4	1.3	.86	Achievement /Responsibility 47%	Unity Togethernes s 54%	28.6 % (4)	0
Otto Pearson	47	31	2.4	1.2	.65	Achievement/ Responsibility 50%	Caring/Hel p 46%	25% (5)	0
Vicki Walsh	40	40	4.6	.91	1.45	Achievement/ Responsibility 57%	Unity Togethernes s 40%	20% (2)	0
Andy Baker	27	21	4	1.2	.92	Achievement/Responsibi lity 57%	Love Friendship 55%	9.1% (1)	9.1% (1)

Table 4.1 (continued)

	LG S	GBC C	SL WS	Agenc y Theme s per Scene	Communio n Themes per Scene	*Most Frequent Agency Subtheme	*Most Frequent Communio n Subtheme	% of Redemptio n Scenes per Total Scenes	% of Contaminatio n Scenes per Total Scenes
Ed Frazier	32	21	3.4	.42	1.00	Achievement/ Responsibility (40%) &Status/Victory (40%)	Unity Togetherness 33.3%	18.2% (2)	0
Kevin Little	35	12	3.8	.58	1.33	Achievement /Responsibility 71%	Caring/Help 56.3%	30% (3)	0
Teri Uhl	28	11	3.2	1.3	1.1	Achievement/ Responsibility 46%	Caring/Help 36%; Dialogue 36%	50% (4)	0
Rose Stanton	29	6	3.8	1.1	1.1	Achievement/ Responsibility 42%	Unity Togetherness 40.0%	16.7% (3)	11.1 (2)

*Frequency of agency subthemes in total sample by percentage: Achievement/responsibility-49.4%; Self-impact-23.7%; Power/impact-17.2%; Status/victory-9.7%

Frequency of communion subthemes in total sample by percentage: Caring/help- 31.8%; Love/friendship-30.1% ; Unity/togetherness- 22.7; Dialogue-15.4%

Table 4.2 Group 1 Higher Generative (LGS, 41.8 or higher; GBC, 29.6 or higher)

Name	LGS score	GBC score
1. Carl	57	42
2. Greg	60	41
3. Alice	58	50
4. Irene*	39	42
5. Marlene	48	38
6. Otto	47	31
7. Vicki*	40	40

Table 4.3 Group 2 Lower Generative (LGS less than 42.5; GBC, less than 29.25)

Name	LGS score	GBC score
1. Andy	27	21
2. Ed	32	21
3. Kevin	36	12
4. Rose	29	6
5. Teri	28	11

Table 4.4 General Demographics by Group Membership

Group	Mean Age	Age Range	Gender % Female	Ethnicity/Race %	Active Church Involvement	Living Situation	Work Status %	Involvement in Advocacy %	Parental/ Marital Status
Group 1	46.1	39 years (26-65 years)	57%	Caucasian 86%(6) African-American 14% (1)	71% (5)	Lived alone (29%) Lived with others (family, supervised/ supported living (72%))	Paid/unpaid work (86%) (6)	86% (6)	Parents (28%) (2) Married (0%) Divorced (0%)
Group 2	48.6	30 years (35-65 years)	40%	Caucasian 80%(5) African-American 20% (1)	60% (3)	Lived alone (40%) Lived with others (family; supported/supervised living)60%	Paid/unpaid work (80%) (4)	25% (1)	Parents (0%), Married (0%) Divorced (20%) (1)

Table 4.5 Average score of GBC, LGS and SWLS by group

Group number	GBC Score	LGS Score	SWLS Score
Group 1	40.6	49.7	4
Group 2	14.2	30.2	3.64

Table 4.6 Average score of Agency and Communion by Group

Group number	Agency theme per scene	% of scenes with Agency theme	Communion theme per scene	% of scenes with Communion theme
Group 1	1.00	65	.91	71.6
Group 2	.92	58.4	1.09	73.4

Table 4.7 Overall percentages of Agency Subthemes by group

Group number	Achievement Responsibility	Power/ Impact	Self-insight	Status Victory
Group 1	47.6	15.6	27	9.8
Group 2	51.2	18.8	20.4	9.6

Table 4.8 Overall percentages of Communion Subthemes by group

Group number	Love Friendship	Caring Help	Unity Togetherness	Dialogue
Group 1	31.3	32.1	24	12.4
Group 2	28.8	31.4	21.5	18.3

Table 4.9 Overall percentages of type by redemptive theme by group

	Growth	Recovery	Learning	Improvement (other)
Group number				
Group 1	56%	20%	16%	8%
Group 2	57.1%	21.4%	14.3%	7.1%

Table 4.10 Comparison of men and women by group with Agency, Communion, GBC, LGS and SWLS

Group	% of agency	% of communion	GBC Score	LGS Score	SWLS Score
Group 1 male	57.2	65	38	54.7	4.1
Group 2 male	47.3	69	18	31.7	3.7
Group 1 female	71	73	42.5	46.3	4
Group 2 female	73	80	8.5	28.5	3.5

Table 4.11 Major Findings from Data Analysis

<p>Demographic factors</p> <p>Total Sample</p> <p>The demographics of the total sample reflected the demographics of the population of individuals with mild intellectual disabilities (Snell, et.al., 2009; Croen, Grether & Selvin, 2007; Stancliffe & Lakin, 2007; Anderson, Larson & Wuorio, 2011; Yakami & Fujiura, 2002; U.S. Dept. of Health and Human Services, 2011).</p> <ul style="list-style-type: none">• Income: The majority fell below the poverty threshold.• Living arrangements: Fifty percent lived alone; with the majority living in supervised setting or with family.• Employment: There was a high level of unemployment or employed in part-time and service jobs.• Lifestyle: There was considerable variation in the lifestyle outcomes.• Disability etiology: The majority had undefined etiology of the disability. <p>Higher Generativity Group (Group 1) and Lower Generativity Group (Group 2) Differences</p> <ul style="list-style-type: none">• There were no differences between groups regarding racial composition.• Proportionately there were more women than men in the Group 1 than Group 2.• Group 1 members reported a slightly higher church/synagogue attendance routine than Group 2.• Group 1 had a slightly higher proportion of those who were active in volunteer and/or paid work• Group 1 members were more involved in advocacy work than Group 2 members.
<p>Influential factors related to the formation of identity</p> <ul style="list-style-type: none">• Culturally imposed anchors <p><u>Race:</u> Both African American interviewees' memories were infused with racial content, commonly marked with discrimination or prejudice; Three Caucasian interviewees included racial content in their memories.</p>

Economic status: Those with lower economic status narrated stories and feelings that centered on their basic needs. Those raised in middle to upper-middle class families narrated stories that centered on nurturing their creativity and upward mobility.

Gender : Meaningful qualitative differences did not surface between men and women; although further exploration may yield different results.

Religion: The importance of religion in the identity making process proved meaningful in their narratives. Religious beliefs provided a guide to participating in the world, in terms of generative values and actions. Religious affiliation provided a mechanism for communion.

Disability: One-half of the individuals narrated disability content in their high point scenes, with evidence of self-identified group identity as a person with a disability. Two of 14 low point stories contained disability content. These stories centered on parental reactions related to the diagnosis of Down syndrome. Both stories were redemptive.

Three of 11 persons included disability related themes in their turning point scenes. Of the turning point scenes two were also redemptive.

- Factors of connectivity

Role of the family: Narratives were contextualized with early childhood memories. Two high generative interviewees credited their mothers with continual guidance in their lives. There were varied experiences of the individuals' place in family based on familial circumstances (ex. Parents' focus on education, alcoholism, emotional closeness and support of interviewee).

Mentoring relationships: More Group 1 interviewees than Group 2 interviewees recounted the mentoring influence of nonfamily at transformative points as particularly meaningful and they also recognized the "life cycle process of mentoring", (i.e. serving as mentors).

- *Socio-cultural/historical factors:*, The economic, cultural and political factors, at the national and local levels and within a historical context, contributed to the interviewees' identity making process.

Political factors

- Vietnam War (1960's and 1970's)
- Urban riots (1960's and 1970's)

<ul style="list-style-type: none"> ○ September, 11, 2001 terrorist attack <p>Economic factors</p> <ul style="list-style-type: none"> ○ Urban renewal/destruction of neighborhoods <p>Cultural</p> <ul style="list-style-type: none"> ○ Sports focused city ○ Green movement
<p>Agency and communion</p> <p>Total sample</p> <ul style="list-style-type: none"> • Agency: The achievement and responsibility subtheme (49%) was the most frequent subtheme for the total sample, followed by power/impact (17%), self-insight (24%) status/victory (10%). • Communion: Love/Friendship (30%) was the most frequent subtheme for the total sample, followed by dialogue (15%), caring/help (32%), and unity/togetherness 23% <p>Higher Generativity Group (Group 1)</p> <ul style="list-style-type: none"> • Agency: Both groups narrated agentic subthemes with the same frequency. This group narrated a higher percentage of scenes containing an agentic theme as well as more agency subthemes per scene. This group's stories contained a higher percentage of self-insight than the lower generativity group. • Communion: This group narrated with a higher percentage of love/friendship, caring and unity/togetherness. <p>Lower Generativity Group (Group 2)</p> <ul style="list-style-type: none"> • Agency: This group's stories were told with more achievement/ responsibility and power/impact subthemes. • Communion: This group's stories contained a higher percentage of scenes with communion themes as well as more communion subthemes per scene. There was a higher percentage of dialogue subthemes in this group.
<p>Redemption and contamination</p> <p>Total sample</p>

- Of the total scenes (N=145), 26% contained a redemption theme. Three percent contained a contamination theme.

Higher Generativity Group (Group 1)

- Both groups were fairly evenly matched by percentage of redemption themes and percentage of redemption scenes per the total number of scenes.
- This group produced a higher average redemption score (4.4) than Group 2 (3). The differences were due to additional points awarded for enhanced agency, communion, and ultimate concern.

Lower Generativity Group (Group 2)

This group had a larger percentage of contamination stories, although the contamination scores were low overall.

Differences between men and women

- Group 1 men reported the highest LGS and SWLS scores.
- Group 1 women reported the highest GBC scores.
- Group 2 men had the lowest percentage of agency.
- Group 2 women had the highest percentage of agency.
- Group 2 women had the highest percentage of communion scores.
- The Group 1 men had the lowest percentage of communion scores.
- In each group, women narrated their stories more frequently with agency and communion scenes than did men.
- Women's stories overall had a higher percentage of redemptive themes than men.
- Group 2 men had the lowest percentage of redemptive themes in their narratives.

Qualitative Differences between the Higher Group (Group 1) and Lower Group (Group 2)

- Role of Friends

Group 1 individuals tended to have a broader friendship network and more ties to people in the broader community than those in Group 2.

- Socio-cultural/historical Factors

Differences in story content associated with socio-cultural and historical events occurred between the two groups. Those in Group 1 more often narrated personally meaningful memories within the context of socio-cultural, political or historical delineators than those in Group 2.

- Influence of Disability

The generative activities for Group 1 interviewees occurred within the auspices of disability centered organizations. While some Group 2 members were involved in disability agency sponsored programs, they did not primarily identify their generative activities within the scope of those organizations.

Of the 12 interviews, seven identified as advocates-six of those seven were in Group 1. Six of the seven identified as advocates for persons with disabilities.

Figure 4.1 Agency Subthemes by Total Sample

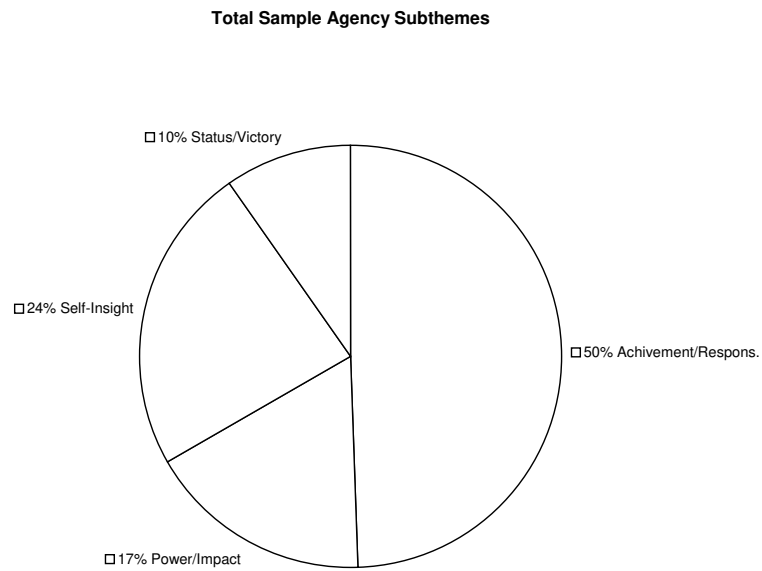
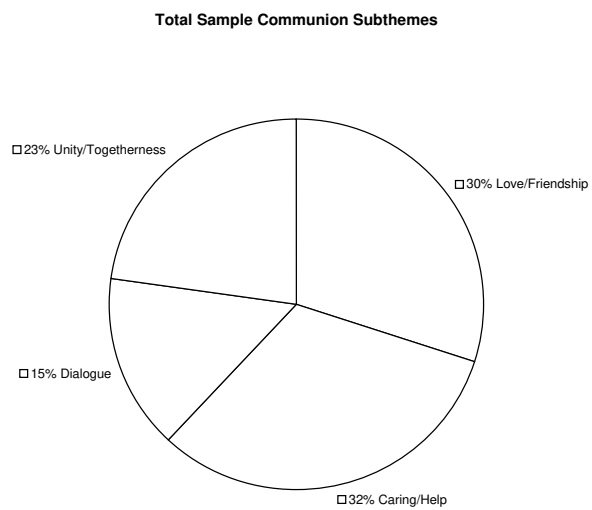


Figure 4.2 Communion Subthemes by Total Sample



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Chapter 5

Discussion

This study recognizes Kluckhohn's and Murray's (1953) wisdom that all people in certain respects are like all others, like some others and like no others.

It is not the answers that are important but the questions - a familiar research adage for all scholars, beginning or advanced. This research was driven by the intent to explore the personal identity making process of persons with mild intellectual disabilities within a human developmental model- one devoid of assumptions related to the lived experience of disability. While disability was not prioritized as the core of the identity making process, analysis of the data, gained through a life story interview format, allowed for the individuals' unique narratives to reveal the place (or not) of disability in their psychological being.

The major findings of this research confirm the importance of studying the life stories of this population. The literature reviewed in Chapter 2 bore ample evidence of the historical dehumanization of individuals with disabilities. For decades, the practice of labeling such persons, minimally as deviant, if not 'nonhuman,' assumed a major presence in American hegemony. This practice thrived in our socio-cultural psyche with continued sustenance from the medical and academic establishments. Current academic work in disability studies continues to live in this compartmentalized world of stigma or deviant driven theory. (Corrigan & Watson, 2002; Finlay & Lyons, 2000; Jahoda & Markova, 2004)

The field of personology or life narrative psychology offers little research regarding persons with mild intellectual disabilities. In human development research persons with mild intellectual disabilities are neither included in the samples of the general adult population nor as an adult subsample. There is little choice for direct practitioners to draw upon theoretical models other than those steeped in stigma. Without a theoretical underpinning, the field of disability services relies on a moral or normative framework in developing and executing its policies and practices.

In recent decades, persons with intellectual disabilities raised the challenge to be seen as *People First*. The research adds empirical evidence to this declaration. *Findings from sampled persons with mild intellectual disabilities indicate that they psychologically engage in an identity making process that is no different than the process which occurs in the greater population of individuals in the United States.*

This research explored questions regarding the identity making process of persons with mild intellectual disabilities. Scientific rigor demands that the researcher considers concepts as discrete units; thus, this research separately explored the concepts of redemption, contamination, agency, communion, and generativity. However, as is the wont of human stories, these concepts intertwine with each other, making it impossible to discuss one concept without discussing another. Recognition of this intertwining suggests possible patterns and connecting themes between the concepts and invites additional questions for future exploration.

This chapter employs two approaches to discuss the major findings. The findings are placed in the context of the research topics and within the larger bodies of knowledge relevant to human development and intellectual disability. Comparisons are made to the empirical research in the fields of narrative or personology and spiritual and moral development. Discussion on the limitations of the study, areas for further exploration and the implication of the research upon the social work, disability studies and narrative psychology fields complete the chapter.

Nine questions prompted the research generated in this study. The questions addressed the researcher's interest, conceptual approach and review of the literature regarding individuals with mild intellectual disabilities.

Research Questions:

1. What experiences influence the formation of identity for sampled persons with mild intellectual disabilities?
2. What are the common themes that offer insight into the developmental processes that lead to
 - a) Communion
 - b) Agency
3. Are there similar and different response patterns of communion and agency within the sample?
4. What are the common themes that offer insight into the developmental processes that

lead to a

- a) Redemptive Narrative Story
- b) Contaminated Narrative Story

5. Are there similar and different response patterns of redemptive and contaminated narrative story within the sample?
6. How do the narrative themes of generativity and stagnation show themselves?
7. Are there similar and different response patterns of the themes of generativity and stagnation within the sample?
8. Are there other contributing factors in the identity making process that are not described by the communion, agency, or generativity?
9. What is the influence, if any, of disability in the experiences of the sampled persons?

Socio-cultural and Historical Influences

This study finds that the overall socio-cultural expectations and historical events that frame the identity making process of Americans also meaningfully influence this process for the sampled citizens with mild intellectual disabilities.

Identity is situated in time and place. McAdams and Pals (2006) delineate five broad principles to explain human functioning. Their last principle acknowledges the differential role of culture in the making of the individual's life story (p. 211). The above finding reflects this principle. As McAdams and Pals explain: "(B) y their very definition, characteristic adaptations are situated in particular social, cultural and developmental contexts. Goals and interests reflect personal investments in activities, programs, and life trajectories that society makes available for the individual" (p. 211).

The authors continue

The complex interplay between culture and human individuality may be most evident at the level of narrative identity. Life stories are the center of culture (Rosenwald & Ochberg, 1992 as cited in McAdams and Pals, 2006, p. 211) Indeed, a person's life story may say much about the culture wherein the person lives as it does about the person who lives it and tells it. Life stories draw on the stories that people learn as active participants in the culture- stories about childhood, adolescence, adulthood, and aging. Stories capture

and elaborate metaphors and image that are especially resonant in a given culture (p. 211).

Analysis of the turning point scenes found that the majority of the non-redemptive scenes focused on socio-culturally important transitional periods, such as moving from one's family of origin to one's own space or obtaining a job. These "typical" Western human developmental transitions to adulthood assumed prominence in the lives of interviewees. In these transitional tales there was not only a physical change present, such as a residential move or job beginning, but a shift in a social and personal identity. One practiced or claimed an adult identity through these important developmental periods. Similarly, the majority of low point scenes reflected the expected story content of family members or friends dying or critically ill.

This study finds that there is a difference in story content associated with socio-cultural and historical events between Higher and Lower Generativity individuals. Interviewees who presented with higher generativity more often narrated personally meaningful memories within the socio-cultural, political or historical delineators than those with lower generativity. The Higher Generativity members' life stories bore witness to their psychological presence in the world around them.

For example, the interrogation of Marlene's (Higher Generativity) life story yielded the finding that her internalized Quaker values directed her motivations and actions as a citizen of the world. In the case of the September 11th terrorist attack, she reframed this national tragedy into a personally redemptive story. This historically transformative event for the nation also initiated Marlene's transformation into personally committing to a moral responsibility to humanity.

Carl's life story reflected the experiences and identity of a typical American male adolescent or young adult. He internalized the identity of an American citizen with a desire to "be a soldier, army soldier...fighting in Iraq." His identity was located in the psychological space of the current historical and political moment. Carl lived out his masculine myth of fame and external recognition by volunteering with a local military support group and coaching a girls' basketball team.

Otto's life story reflected the socio-cultural and historical times of his generation. His memories were replete with the political and racial tensions of the 1950's through the 1970's.

His political astuteness regarding minority representation was evident in his suggestion to me that I interview a young African-American woman for this research.

Otto intimately experienced both the discrimination as a person with an intellectual disability and participation in advocacy movement for persons with intellectual disabilities. These experiences originated first as a sibling of brother with significant intellectual disabilities and later as a self-advocate. At the time of the interview, Otto identified as a senior citizen with a disability and recognized the need to advocate for relevant services for this population.

In contrast to the Higher Generativity Group, the Lower Generativity Group members did not tell the majority of their stories through a historical or socio-cultural lens. Kevin's life story and to some extent Ed's story, stood out as exceptions. Kevin clearly articulated the impact of socio-cultural influences and expectations on his identity making process. As an African-American man living in the central city of a mid-size urban area, he experienced poverty, prejudice and a feeling of constant peer pressure, "to live on the streets."

Ed's stories of his early childhood evoked a melancholy for a racially diverse neighborhood, in which children, black and white, played together and the streets were safe for everyone. This remembered idyllic life was disrupted by the geo-political resettlement of poor people in urban neighborhoods. While remembering his past in this manner, his present evidenced no advocacy related to racial tension or economic disparity.

This study finds that many of the interviewees articulate an astute political understanding of the world around them. This finding bears witness to the reality that past and present socio-political issues influenced the thinking, feeling and generative actions of the interviewees.

Many young Americans share Marlene's rich vision of thriving in a culturally diverse, environmentally conscious and locally sustainable community. Marlene acted upon this vision by her personal food choices and challenging herself to new cultural experiences. Greg understood the political reality of power and money when fighting poverty. He articulated the reality of scarce funding and priority setting by those with political power. Greg addressed the problem of homelessness and drug addiction by providing them with food, money and shelter. Ed worried about the local issues of a casino opening near the criminal justice center and the potential crimes related to such. He also reiterated the concern of many American citizens regarding the absence of fathers in children's lives, illegal drug use, and reduced government

benefits for the elderly and persons with disabilities. He personally offered his time, support and money to his friend - a single mother. On a personal basis, Irene experienced police discrimination against her deaf brother. To fight this institutional discrimination and ignorance she committed herself to achieving a college degree in criminal justice. Kevin spoke of overt discrimination and prejudice he experienced from whites. Kevin's counteraction was to continue reaching out to all persons and letting them get to know him on a personal basis. Otto's political awareness primarily centered on disability related issues. He was acutely aware of the present politics of funding services and legislation. He also possessed a sophisticated historical political awareness of the violence perpetrated on individuals with intellectual disabilities. He shared his recollection of

in the 50s toward 50s, 60s my brother was in (name of institution). I see kids, girls having babies when I was over seeing my brother. The doctor took the kids away just like they did in Germany. Interviewer: So you saw girls that were at state institution) that were pregnant, had children and the doctors were giving the babies away and... Otto: No, no, no, no, taking the babies. Interviewer: Taking the babies. Otto: Just like they did in Germany. Interviewer: Like they did in Germany. Otto: And that was US. Interviewer: Did you mean abortions Otto or you mean the babies were born and they were just taken from the mother? Otto: Taken away and the babies was, (pause) like did the tests. The babies was not – nobody's seen the babies after

Otto related that doctors at the institution stopped his brother's seizure medication and pulled his teeth, without medication, to stop his teeth grinding. "The doctor took them away. He had to save money, so they could save money not give it to him." He also shared that patients en masse received "fire hose" baths. For Otto these extremely personal experiences provided the beginning of a redemptive story for his generative life.

Influence of religion. *This study finds that for the persons interviewed the influence of religion impacts the identity making process.*

This study finds that interviewees' religious beliefs, such as faith in Jesus or God's will to direct one's life, appeared in many of the life stories, oftentimes in the turning point scenes. Additionally, the religious scenes frequently read as redemptive tropes.

Individuals in this research claimed a religious base, as do most Americans, although their report of church attendance was lower than general population reports (Goodstein, 2002 as cited in McAdams, 2006, p. 147; Sherkat & Ellison, 1999). Ten of the twelve interviewees (83%) identified a religion or faith, with three (25%) claiming church participation.

The interviewees' faith based narratives exemplified the importance of a faith community which provided a strong support system for common beliefs and resultant action as well as a psychological home for comfort and emotional connections (Fowler, 1996).

Research exploring the influence of religiosity in the lives of individuals with intellectual disabilities confirms the above findings that participation in religious activity of individuals with intellectual disabilities fulfills the need to feel connected to a spiritual anchor, to feel a sense of belonging and to feel a sense of commitment to help others. (Gaventa, 2005, 2012; Hoeksema, 1995; Lifshitz & Katz, 2009)

The importance of religion in the identity making process proved meaningful to many of the interviewees. Alice, "saved" as an adult identified as a devout Christian. Greg identified as God's servant, as a result of his multiple unsuccessful suicide attempts and recovery from drug overdoses. Both credited God with the advocacy and missionary work that they did.

Alice makes an important distinction between intrinsic and extrinsic religious values.

When I found Jesus. See, I was growing up always have Jesus in my heart. But I didn't have a place in Church. 'cause when you're little, you have to go to Church 'cause your mother makes you go to church. It's get up in the morning, get ready and go to Church.

Marlene and Teri framed their religious inculcation differently than Greg and Alice.

Rather than experiencing a conversion, Marlene and Teri experienced a more traditional indoctrination of Christian beliefs. They considered their religious upbringing, as a Quaker and Presbyterian respectively, as central to how they participated in the world, in terms of their generative values and actions. Like Greg and Alice, they internalized their Christian beliefs into a working model of generative action.

For Rose, Vicki and Andy, religion offered a more communal opportunity. Participation in church services, missionary work, celebration of holidays and church sanctioned festivals provided emotional and physical connections with family and friends.

Religion also produced a source of psychological tension within the identity making process for a few interviewees. Rose perceived this tension as a contamination memory. Her grandmother disowned Rose, who was the product of a Jewish father and Gentile mother. This rejection influenced self-perception as an exile or “other.” However, she also incorporated many Jewish traditions into her sense of self as well as her fundamental Christian beliefs.

For Otto, Jewish law prohibited him to fully claim himself as a Jew due to his disability. Throughout his life story, he reaffirmed not only his Jewish identity but also his identity as a resistance fighter for recognition within the faith. Otto’s and Rose’s heavily religiously layered identities speak eloquently about their generational historical cohort when religious affiliation provided a strong identity marker.

This study finds that differences occurred between the Higher and Lower Generativity Groups regarding religious influence on the identity making process. In the Higher Generativity Group, a strong religious influence on the identity making process was evident in the three of the seven (Marlene, Alice, and Greg) members; while one Lower Generativity group member (Teri) reflected this same influence. Pargament’s (2002; 1992) and Hill’s work (2000) on the positively related quality of life indicators for persons who have intrinsic religious values rather than extrinsic religious values appears to merit further investigation in this research. The individuals mentioned above displayed characteristics of intrinsic values and positive religious coping.

According to Pargament,(2002) “(I)ntrinsically religious people show higher levels of well-being, sociability, and intellectual flexibility, and lower levels of depression, anxiety and social dysfunction than extrinsically religious people” (as cited in McAdams, 2006, p. 154). When faced with crisis, those with positive religious coping strategies seek help through prayer, social support and imagine the positive from a negative situation. (McAdams, 2006, p. 154).

While several higher generativity individuals exemplify religiously intrinsically oriented individuals, only Ed in the Lower Generativity Group represents Pargament’s description of a religiously extrinsically oriented individual, as evidenced by his fear-based beliefs infused with themes of passivity and fatalism.

Influence of alcoholism and addiction in life narratives. *This study finds that the three life stories meaningfully influenced by the effects of alcoholism also carried strong themes of religiosity. Rose credited her father’s recovery from alcoholism to his religious conversion to*

fundamental Christianity. Greg and Teri saw God's hand in their recovery process and subsequently considered their lives directed by God's will.

This study finds that the alcoholism narrative meaningfully influenced the identity making process for those individuals who either identified as alcoholic or who lived with an alcoholic parent. The alcoholism narratives included redemptive themes rather than contaminated themes.

Teri's narrative shares features to the life stories of alcoholics described by McAdams (2006). She faced the challenge of recreating a positive and coherent story; one that integrated a caring social environment that allowed her to opportunities for generativity (McAdams, 2006, p. 228). Like others struggling with alcoholism she "surrendered to a higher power" and let God lead her life. Teri's internal motivation for generative actions, such as serving on the Board of a disability organization and assuming a public speaking role, were supported by her strong spirituality and adherence to Alcoholics Anonymous beliefs.

Influence of spiritual guardians (significant family members). *This study finds that some interviewees found spiritual or psychological guidance in incorporating the memories of their deceased family members into their sense of self.*

A theme of spiritual guidance appeared in three of the Higher Generativity Group and in one member of the Lower Generativity Group. Individuals described the powerful influences that their parents and grandparents held in their lives. Alice vividly detailed her grandmother's gift to her to see the future and how this reinforced her identity as a powerful woman. "I think that's how I can do a lot of stuff, because I have her in me and what I say, I mean that." Alice credited Jesus and her grandmother for helping her through her cancer treatments and declared "I got the power." Otto felt his deceased mother's presence "many, many, many times" in his life, particularly when he spoke to groups. He recalled speaking in Washington D.C. to a group of doctors "and I feel- and I feel like my mama is back of me giving the talk". He also shared a poignant moment of seeing his mother's book about the early years of the Association for Retarded Citizens and how proud he felt. He wanted to write "just a small book," which would join his mother's book in the Library of Congress.

Influence of economic status. *This study finds that the marker of economic status contributed to the identity making process in the interviewees' life stories; the influence of lower economic status explicitly foregrounded much of the life story for the two most economically*

disadvantaged interviewees. Those with lower economic status (Kevin and Greg) narrated stories and feelings that centered on their basic needs, whereas those raised in middle to upper-middle class families (Carl and Marlene) shared memories centered in nurturing their creativity and upward mobility.

Influence of experiences with family and friends. *This study finds that the intimate family experiences universal to all human development contributed to identity making process of the interviewees. This study finds that individuals in the Higher Generativity group narrated more positive stories about their families of origin than did Lower Generativity group members.*

The individuals' narratives of these intimate experiences contextualized the interviewees' perceived role in the family. For example, Marlene's childhood memories centered primarily on her role as a sibling, child or grandchild-- not as a family member with a disability. Within her family, she felt loved and challenged to express her creativity, a characteristic valued by the family. Andy, however, contextualized his family centered stories with an emotional overlay of feeling "different" and patronized by his parents and sibling. Teri's and Rose's life stories included a history of family dysfunction related to parental alcoholism. In her adolescence, Teri confronted her "differentness" and her mother's consistent negative focus on her disability by joining a peer group of "normal kids who drank."

Agency and communion. *This study finds a tentative relationship between agentic and communal early childhood narratives and gender of the interviewee. This difference surfaced most often in the childhood memories- four of five Higher Generativity individuals whose childhood memories did not contain agency were women. Conversely, men's childhood memories lacked communion. This finding possibly reflects the social construction of gender related narratives and invites future study.*

This study finds that, older interviewees, who identified themselves as advocates narrated a stronger theme of agency in their high point scenes than those younger interviewees who engaged in disability related activities. This finding possibly reflects the difference in developmental stage between younger and older interviewees. Conversely, these younger interviewees narrated from a stronger communion voice than their senior counterparts.

This study finds that the interviewees narrated their high point scenes predominantly through an agentic rather than communal filter. Individuals with intellectual disabilities live within the American cultural geography of preferring individuality and self-achievement.

Redemption and contamination. McAdams and Bowman (2001) and McAdams, Diamond, et.al (1997) confirmed a prevalence of redemptive imagery in the life stories of highly generative adults. Individuals whose stories contained more contamination were less optimistic and fixated on the past (McAdams & Bowman, 2001). Additionally they found that at least one explicit contamination sequence was narrated by the 260 midlife adults interviewed (McAdams and Bowman, p. 19). In this present study, *the Lower Generativity Group members had a larger percentage of contamination stories (5.2%) than the Higher Generativity Group I (1.2%).* From a qualitative perspective it did not appear that the individuals with contaminated stories narrated their life stories with less optimism or fixation on the past than other interviewees; however, this study did not specifically measure level of optimism.

This study finds that overall 24% of the total stories analyzed contained a redemptive themed story. Eleven of the twelve interviewees narrated a least one redemptive story. The majority of interviewees' turning point scenes and low point scenes revealed themes of redemption signifying a proactive and positive identity making process.

This study did not find a stronger relationship between Higher Generativity and redemption and the Lower Generativity Group; the Higher Generativity Group had a slightly higher percentage of redemption scenes (25.3%) compared to the Lower Generativity Group (22.4%). However, individuals in the Higher Generativity Group narrated their redemptive stories with a deeper sense of agency, communion and ultimate concern than the Lower Generativity interviewees.

McAdams and Bowman (2001) concluded that “(T)he characteristic ways that people narrate important turns in the perceived course of their lives may speak broadly to the overall quality of their lives” (p. 25). In later research, McAdams (2006), stated that “(I)t should not be surprising to learn, therefore, that the redemptive self may often incorporate a spiritual dimension” (p. 145).

A relationship between redemptive stories and scores from the three quantitative instruments was found in the Higher Generativity Group. Those with the three highest

percentage of redemption scenes had a higher average SWLS score (4.7) compared to those four with lowest percentage of redemption scenes whose average score was 3.6. This comparison held true for GBC and LGS; the averages of those with the three highest percentage of redemption scenes had higher scores on GBC and LGS. The subgroup with higher frequency of redemptive stories (Alice, Greg, Marlene) narrated with more growth, recovery and learning content than did the lower frequency group (Otto, Vicki, Irene, Carl). This last group's narrative contained more themes of improvement.

Women's stories on average had a higher percentage of redemptive themes than men's stories (32.3% vs. 23.5%). Men in the Lower Generativity Group had the lowest percentage of redemptive themes in their narratives.

Generativity and stagnation. *This study finds that more adults in the Higher Generativity Group narrated life stories with consistently strong and intrinsically driven religious content than in the Lower Generativity Group. The influence of religious belief also provides answers to the questions centered on generativity and stagnation. McAdams (2006b) in *The Redemptive Self*, stated that generativity in America is often also linked to religion. (p. 155). He stated,*

research shows a positive statistical correlation between measures of generativity, on the one hand, and indices of religious and spiritual involvement, on the other. Adults who report regular church attendance, frequent prayer or meditation, and concern about religious or spiritual issues tend to score higher on measures on generativity, on the average than those adults who do not express high levels of religiousness and spirituality. Furthermore, adults high in generativity also tend to report that as children they were raised in religious households and involved in religious institutions, to a greater extent than adults low in generativity (p. 155-156).

Complementing the earlier discussion, the Higher Generativity group, included more adults who exemplified McAdams' (2006) finding that adults who are highly generative, are more likely than those scoring lower on generativity measures to claim that they internalized a coherent system of beliefs and values. They are more likely to say, that, though they have changed and grown in many ways over time, those same values have remained strong and true. (p. 157)

Marlene's, Greg's and Alice's stories speak directly to McAdams' (2006) findings of highly generative life stories that "suggest moral clarity and steadfastness" (p. 158). These individuals shared the features of moral commitment and a deep sense of confidence in living a generative life found in McAdams' (2006) and Colby's & Damon's (1992) research. Their religious beliefs provided the ideological setting for their generative commitment and action.

This study did not confirm McAdams' (2006) finding that "involvement in religion as a child is positively associated with measures of adult generativity" (p. 163). Three of the seven interviewees who narrated childhood or adolescent stories with religious content placed in the Lower Generativity Group. This finding may be a function of the small sample size and needs further investigation.

In *The Redemptive Self*, McAdams (2006) provided an extensive overview of adult generativity research. Discussed here are findings relevant to the present study. McAdams (2006b) cited earlier research (Hart et al., 2001) that found that "(a)dults high in generativity have broader friendship networks and perceive that they are more closely tied to other people in their communities, compared to adults low in generativity" (p. 157).

This study finds that Higher Generativity interviewees tended to have broader friendship networks and more ties to people in the broader community than Lower Generativity interviewees. Although this relationship between high generativity and broader friendship networks and closer community ties was not directly addressed in this study, initial analysis of the each group's friendship networks and community ties lends credence to Hart's et al. finding. Six of seven Higher Generativity members actively participated in community oriented groups. Community oriented groups included, advocacy groups for persons with disabilities, advocacy groups for persons who are homeless, women's writing group and a program which taught art to students with disabilities and a program which offered social and volunteering opportunities for persons with disabilities. From the interviewees' narratives a theme of meaningful friendships and ties to the larger community evolved. Their generative activities involved broad social commitments and placed them in a consistently self-reinforcing environment for continued generativity and positive identity making.

In the Lower Generativity Group, two of the five were considered active in community oriented groups, including advocacy work and Alcoholics Anonymous. Two other individuals narrated stories of strong extra-familial relationships, however, these were limited to a smaller network of work related friends or close neighbors.

McAdams reported that, “(A)dults high in generativity are more involved in religious, political and civic venues, compared to those lower in generativity” (Cole & Stewart, 1996; Hart et al., 2001; Peterson, 2002 as cited in McAdams, 2006, p. 57; Peterson & Klohnen, 1995; Peterson et al., 1997; Rossi, 2001). *This study finds that members of the Higher Generativity Group were more involved in religious, political and civic venues, compared to those in the Lower Generativity Group.* As noted above, while the intensity or breadth of civic, religious, and political engagement was not measured in the present study, initial findings suggest that those with higher generativity did participate more in the above venues than those with lower generativity. The nature of the advocacy work in which many of the individuals in the Higher Group were involved provided an opportunity for involvement at the local, state and national levels.

McAdams reported on a finding that “(H)ighly generative adults report higher levels of happiness and life satisfaction, lower levels of depression and anxiety, compared to less generative adults” (Ackerman & Zuroff, 2000; de St. Aubin & McAdams, 1995; Grossbaum & Bates, 2002 as cited in McAdams, 2006, p. 57; Keyes & Ryff, 1998; McAdams et al., 1998; Peterson et al., 1997; Snarey, 1993; Vaillant, 1977; Vandewater et al., 1997). *This study’s small sample size did not allow for reliable statistical comparison of the satisfaction with life indicator.*

When considering the conduits for generative motivation and behavior, the role of mentoring was an unexpected finding of this research and opened up possibilities for further exploration. *This study finds that the influence of mentoring is evident in the life stories of highly generative interviewees.* Otto and Alice, two of the oldest and most generative interviewees, provided valuable insight into the influence of a mentoring relationship upon generative motivation and action. For both, the mentoring relationship began in adulthood. Alice shared a cab daily with a career woman, older than she and with a disability. She often shared the hurtful remarks that she overheard from her work peers and the emptiness she felt in her clerical job.

She credited this series of conversations in the cab rides home with changing her life. Alice stated that the woman with whom she rode a cab home from work, told her, “you know you can do something better than what you’re doing.” Initially, Alice did not believe this woman, “And I said, ‘Ha ha ha ha ha!’” However, overtime she acquired seeds of confidence and psychologically grew to challenge herself to begin an advocacy career. For Alice, this woman greatly influenced her self-identity. Alice’s career change transformed her into a powerful advocate who won numerous local and state awards and educated and motivated other persons with disabilities throughout the U.S.

At the time of this interview, Alice continued this generative cycle and considered herself an influential mentor to a younger woman with a disability. In her role as mentor, she stated that she shared,

My wisdom, when I talk to May, I tell her a lot of stuff...I think I tell a lot of wisdom I want her to know, what I want her to learn. It’s funny because she is 34 and I’m 63. It’s much different ages.

Otto identified an older man, not disabled, but in a power role as an advocate for persons with disabilities, who challenged him to be more - to become an advocate. At the time of the interview, Otto shared numerous stories of encouraging youth and young adults with and without disabilities to set high goals and to not allow others to direct their lives. In one example, Otto shared a talk he facilitated with children who had lost parents in the Oklahoma Federal Building bombing. Otto’s message to them was, “You could do stuff.” He continued, “(Y)ou cannot say no to help with the girls, boys.” Like Alice, Otto travelled to many schools and conferences encouraging persons to try their best and not to be discouraged. Also, Otto, on a more individual level assisted young adults with intellectual disabilities with major life decisions such as having children. As Otto stated, “I’ve helped a lot of people through the years. You know like working with that girl that call me every other day what’s her supposed to do.”

This study finds that the identity as advocate was integral to approximately one-half of the interviewees and provided a rich source of generative opportunities. The Higher Generativity Group included five of the six interviewees who self-identified as advocates.

The Generativity Behavior Checklist addresses behavior, one of the three related characteristics contained in the concept of generativity. *This study finds that the average GBC*

score of 46.3 of the six advocates was considerably higher than the average score of 40.6 of the Higher Generativity Group.

This study finds that belonging to and actively participating in disability-focused advocacy gave meaningful purpose to interviewees. Additionally, interviewees who were active in advocacy for persons with disabilities were cognizant of the shared goals and purpose of their work. Advocacy provided a meaningful connection to others, politically, socially and emotionally.

In general parlance, advocacy refers to an action to bring about a desired change. Advocacy may occur at the micro, mezzo or macro level. *This study finds that many of the interviewees shared an experience classified as micro advocacy.* For example, Teri shared that she advocated for her roommate at times with the house staff. The action occurred due Teri's personal connection with her roommate and her perception that her roommate was unable to speak for herself.

Others, such as Otto, advocated for individuals at the mezzo level, not because of their personal connection but rather due to their broader commitment to helping others with intellectual disabilities. Otto's experiences represented advocacy at the mezzo level, in which he advocated for the choices and rights of individuals with intellectual disabilities to authoritative bodies or persons, such as families or physicians. Otto served on committees and participated in family and medical meetings, which considered issues such as pregnancy and terminal illness of persons with intellectual disabilities.

For one-half of the interviewees, advocacy also occurred at the macro level. Llewellyn and Northway (2008) described this level of advocacy as more educational or proactive in its approach and potentially impacting a larger group. High point scenes for four of the six advocates contained macro level advocacy content.

This study finds that generative action, which included macro level advocacy, also contained a theme of interviewees' personal connectedness to the cause as well as to others. Carl, Alice and Otto, among the youngest and oldest advocates, independent from the other, talked proudly about the eliminating the "R word" (retarded) in state official language. Alice recalled the scene in which the governor signed a bill that outlawed the use of the word. She stated, "I was at the table when he signed a bill taking away the "R" word, he was very honest,

very nice and he always remembered what my name was.” Carl referred to this as the BAD WORD, something that he could not say. He stated that he fought for this, “(T)o fight for my rights.” Otto referred to his advocacy as fighting for “us” or “us people”. His struggle consciously moved from the individual politic to the larger political world.

Marlene recognized herself in the lives of her young art students with autism. She considered teaching a high point of her life, allowing her to positively impact the young lives of individuals like her and to make a living from what she loved.

This study finds that participation in disability specific activities and organizations provides opportunities for entrance into the community at large and participation as citizens. For example, Carl identified himself as American and felt strongly about “supporting the troops.” His participation in a disability specific organization offered him the opportunity to act upon his motivation by volunteering for a “yellow ribbon” support group. As mentioned earlier, Marlene exhibited and sold her artwork to the community at large through her participation in a disability specific arts organization. (Note: It is important to acknowledge that the expressed mission of these organizations was to support community inclusion.)

This study finds that generative actions of the interviewees extended beyond advocacy and were typical of the general population. Examples of non-advocacy related generative actions included parenting, volunteering, participating in church activities and pursuing educational goals.

The lived experience of mild intellectual disability. The majority of the identity making themes present in the turning point, low point and high point scenes did not contain disability related content; but rather themes present for any American citizen. *This study finds that for those scenes infused with disability content, many of the interviewees recreated these memories with a redemptive theme - reframing a negative incident into a positively reconstructed memory. The redemptive subthemes expressed a self-awareness.*

Additionally, this study finds that for those scenes in which the interviewees preferred their disability, the scenes were more often told as a high point rather than low point story. The disability related high point scenes of the Higher Generativity group contained more themes of agency than the Lower Generativity Group, who carried a strong pattern of communion themes. This finding suggests that experiences that are related to one’s disability are not negative but

rather positive and promote a sense of agency for those individuals with high generativity. In this study cause and effect are not suggested, rather a relationship is noted.

One-half of the individuals included disability content in their high point stories.

Alice and Otto, two highly generative adults and two of the most active advocates, shared a long history of personal experiences, which they directly connected to advocacy or disability. *Their life stories were deeply infused with disability related content.* All five of Otto's high point scenes revolved around his identity as a person with a disability; two of Alice's three scenes did the same. Alice's high point stories reflected three times as many agency themes as communion scenes and 100% of Otto's themes were agentic.

The idea of a shared group identity surfaced during qualitative analysis. Disability scholars have devoted considerable thought and research to a developmental model of group identity. (Fine & Asch, 1988; Gill, 1997; Hahn, 1997; Weeber, 1999) This discussion is saved for further exploration and is beyond the scope of this research.

Limitations of the study. The small sample of twelve individuals limits the generalizability of the findings to the population of individuals with mild intellectual disabilities. Additionally, the story making of these individuals takes place within the historical and socio-political-cultural context of a Midwestern urban city. Although analysis explicated data by race and gender these findings serve only to raise future research possibilities.

Within the study itself, the factor of race on the identity making process and comparisons between interviewees cannot be fully explored due to only two African-Americans in the sample. However, the individual stories of these African-Americans do offer insight into how race influences the identity-making process. This study did not include individuals from other racial or ethnic groups further limiting its generalizability.

The level of advocacy work in which some of the interviewees engaged is atypical of the at-large population of individuals with mild intellectual disability. Also atypical of the at-large population of individuals with mild intellectual disability is the level of support services received by the sample; a product of the recruiting process (Snell et al., 2009; Sullivan & Adock, 1999).

Limitations related to data collection and resultant data analysis include the potential for errors during the interview process; such as the interviewee not understanding the question or the interviewer not understanding the response. The interview process itself is an act of

interpretation (Roberts & Rosenwald, 2001). Added to the challenge of single case analysis is the interpretative challenge of a multiple-case study. Procedures outlined in Chapter 3 acknowledged this potential limitation and the procedure put in place to limit these reliability issues.

Areas in need of further study. The exploratory nature of this study-- both in terms of small sample size and the conceptual parameters placed on the data analysis-- invites further study. An important discovery in this research is the meaningful impact of religion or spirituality in the identity making process of persons with mild intellectual disabilities. In the area of spirituality and religion many opportunities for research exist, including exploring the benefits of religion related to social attachments and achieving a sense of community; exploring the impact of religion on the personal meaning making; further exploration of the differences in intrinsic and extrinsic religious values exploration of the relationship of generativity to satisfaction of life; and the relationship between religious beliefs and social advocacy. The work of McAdams (2006b) as well as research conducted by Northwestern University's Foley Center for the Study of Lives offers a rich basis of comparison with the general adult population for further study with persons with intellectual disabilities.

Other future research areas include a more in-depth understanding of the intersection of categorical identities of persons with mild intellectual disabilities, including race, gender and economic status. Also in need of further research is the role of alcoholism in the lives of persons with mild intellectual disabilities. The influence of alcoholism was apparent in several of the life narratives of the interviewees: either as an intimate witness to parental alcoholism or as a user of alcohol and other drugs. Carroll-Chapman and Wu (2012) noted that 7-8 million U.S. citizens with intellectual disability experience substance use problems. In a literature review investigating the prevalence, prevention and treatment of substance abuse, they found that while the prevalence of alcohol and illicit drug use were low, the risk of having a substance-related problem among ID substance users was comparatively high. They encouraged research to better assess the magnitude of the problem, identify prevention and specify treatment components which address the "unique needs of the population" (p.1147).

This study was not designed to measure the relationship characteristics of quality, depth and breadth of friendships and community connections. However, further research would add to

the understanding of how characteristics of social embeddedness factor into one's relational identity of persons with mild intellectual disabilities.

The finding of the presence of mentoring in the lives of highly generative interviewees deserves further study. Of interest is the further exploration of the importance of mentoring and the possibility of creating a developmental model of the mentoring process (from mentee to mentor) in the lives of persons with mild intellectual disabilities.

In the field of psychology, the concept of resiliency shares common features with narrative psychology's concept of redemption. Incorporating the life story methodology and theoretical concept of redemption into the exploration of resiliency with individuals with mild intellectual disabilities is an area for future research.

Lastly, the social identifier of disability, specifically mild intellectual disability, appeared in many iterations throughout the interviewees' narratives. As mentioned above, further exploration of the development of a group disability identity for highly generative individuals is warranted.

Implications of Research

This research adds evidence to the limited body of empirical study of the identity making process of individuals with mild intellectual disabilities. Findings from this research speak to the typicality of the developmental process inherent in lives of persons with mild intellectual disabilities. This research offers academicians, policy makers and practitioners empirical findings rather than normative based arguments that the provision of opportunities for full community engagement for persons with mild intellectual abilities results in highly generative citizens.

Research application of the life story framework. This research addresses knowledge building in theory and practice. To date, there is little empirical study of persons with mild intellectual disability employing a life story framework. This research offers a successful methodological application of the life story interview format and the theoretical application of the meaning making process through exploration of significant personal memories with this population. With wide eyes and open ears, this research listened to the individual stories of persons with mild intellectual disabilities with an assumption of human development theory, rather than the prevailing stigma influenced model. This exploratory research finds that this

sample of persons with mild intellectual disabilities *psychologically engaged in an identity making process that is no different from the process which occurs in the greater population of individuals living in American society*. The life story/narrative psychology concepts of agency, communion, redemption, contamination, generativity and stagnation are useful and viable concepts in understanding the lives of persons with mild intellectual disabilities. This research serves as an example to others interested in understanding the lives of persons with mild intellectual disabilities and to those working to expand the theoretical application of narrative psychology. Use of the life story approach reflects the best practice in exploring the lives of marginalized persons and allows their voices to inform researchers and practitioners.

Implications of research for the field of social work. This study offers an example of the successful use of a mixed method approach. The empirical findings are strengthened by the application of qualitative and quantitative instruments. The research findings address the recommendation of the American Association on Intellectual and Developmental Disabilities and The ARC to prioritize applied and basic research related to intellectual and/or developmental disabilities. In a joint position statement the AAIDD and The ARC supported research-based best practices (Disabilities & ARC, 2010).

The seven-year-old statement by the National Association of Social Workers' Social Work Policy Institute may indicate the social work field's lack of urgency or commitment to the research in the field of developmental disabilities. To their credit, at that time, the Institute encouraged social workers to continue "to direct their research toward making the lives of those who experience disabilities more just and fulfilling (Social Work Policy Institute, 2007)."

Implications for Policy

Government policy. This research foregrounds the policy discussion within a human development framework. As a result of such a paradigm shift, individuals with mild intellectual disabilities are understood within an inclusive model of human needs rather than a deficit model of need for a special population.

Fujira and Parish (2007) note that the demographic trend of the aging of the baby boomer generation impacts the future policies for persons with intellectual disabilities. They present a core challenge for policy makers: "develop appropriate service and care models,

managing health and securing and organizing public financing (p. 188). Additionally, they note that

due to the technological and health care advances realized during the last century, the first generation of U.S. adults with intellectual disabilities is beginning to outlive their parent caregivers in large numbers....In their current configurations service systems are ill equipped to handle the increase numbers of elderly people with intellectual disabilities who will require care from an increasingly strained service system. (p. 189).

For many individuals with intellectual disabilities, the Medicaid waiver program, a federally subsidized program, provides the funding for service supports. As Ohio Director of Developmental Disabilities John Martin (Martin, 2013) explained to the House Committee on Finance and Appropriations Health and Human Services Subcommittee, “The DD system is funded through a unique combination of local, state and federal dollars”. Like many states, Ohio continues the conversion process of “...allowing funds to flow to the individual and enhancing their ability to choose where they live and work, and who provides their services to them (p. 2).” Director Martin testified that the state relied heavily on Medicaid Home and Community-Based waivers to fund a substantial part of the DODD service delivery system. (p. 3). These waivers allowed individuals to participate in community life. He noted that the use of these waivers since 2011 have increased from 5,663 to 27, 802 in 2012, a gain of 391 percent (p. 3). Additionally, in 2012 Ohio initiated a Medicaid funded waiver, the Self Empowered Life Funding waiver. Under this waiver, “individuals can direct how “how they receive services (p.3)”. As Martin explained, “The new SELF waiver is the next evolution in understanding how to support individuals not just where they live (p. 3).”

As Fujaira and Parish (2007) noted, “(T)he structure of intellectually disability services reflects this fact of federalism: the most notable feature of service is how variable states are in their fiscal commitment and in the character and quality of services (p. 191)”. The opportunity to impact policy changes can occur at three levels, local, state and federal.

This research provides a theoretical direction for change strategies impacting policy. Such change strategies might include: a focus on strength based programming and accountability which incorporates the life story and human development models. Waiver funding requires an

individualized plan, centered a person's strengths and wishes. These plans, predicated on assessments could incorporate the life story model, which underscores the individual's personal sense of, and desire for, agency and communion. Funding could reward those opportunities or activities which recognize the process of typical human development and recognize the need for unity and purpose in one's life. As Director Martin testified, governmental level policies should encourage fully inclusive community participation. The qualitative measuring stick for policy success is one's identity as a citizen not as a person with a mild intellectual disability participating in the community. Such opportunities for citizenship take into account the total person, including gender, race, religion, family experiences and the historical time and place.

Program policy. This study found that interviewees narrated their lives with pride, confidence and mastery. It is recommended that persons with mild intellectual disabilities assume roles of responsibility in all parts of their life. Programs should create and encourage individuals to experience the assumption of important responsibilities. The second most frequent agency subtheme, self-insight, suggests that individuals with cognitive disabilities take away 'life's lessons' from their experiences. Opportunities for genuine introspection, for example, the women's writing group described by an interviewee, address the desire and ability for self-awareness and understanding. Providing motivational public speaking experiences also encourages self-awareness and introspection as well as an opportunity for power and impact.

Less evident in the stories are the themes of power/impact and status/victory. Implicit in these last two themes are one's influence on others or recognition from others. The implications for programming include allowing for opportunities of honest/legitimate victories.

Interviewees often narrated a life with close friends and family; they felt cared for and loved and loved and cared for others in return. However, the communion subtheme findings showed a lack of unity/togetherness and dialogue. Findings regarding the communion subthemes, suggest a need to belong to the world at large, to share a sense of unity and togetherness. Volunteer citizen opportunities should be promoted. Ironically, one method of reaching this goal of full citizenship is through disability organizations. Full citizenship offers opportunities, for agentic and communal activities which lead to a generative life - a life with purpose and unity. The key to this success is that the disability organizations have full inclusion as its mission and practice.

Participation in church activities and a sharing of fellowship with other like-minded individuals resounded through the narratives. Churches should welcome this involvement and provide genuine opportunities for individuals with intellectual disabilities regarding education about its mission and purpose and fellowship experiences which reflect its mission and purpose.

Least frequently narrated was dialogue (15.4%). Dialogue involves a reciprocity or communication with one other or with a group. Dialogue implies a more active form of unity. Policy implications for this finding corroborate the previous recommendation that individuals have experiences that stress “being with” rather than “doing for”, for example the women’s writing group, or church group focused on reflection.

Social Work Education

These research findings call for social work education to reconceptualize persons with mild intellectual disabilities within the human development model, rather than the traditional deficit or rehabilitative model. The governing body of social work education, Council on Social Work Education (CSWE), experiences an ambiguous relationship with the concept of disability. CSWE declares that it views disability within a diversity or minority model; however, in social work education’s curriculum construction, disability is typically taught within the traditional medical framework, primarily focused on quality of life issues or as a “special population” (Council on Social Work Education-Council on Disabilities and Persons with Disabilities, 2013). This perspective and practice significantly lags behind the academic fields of the humanities and social sciences that recognize disability as socially constructed.

This research answers a call issued by CSWE for the dissemination of work which influences the curriculum about social work practice with persons of disabilities, programs and services that improve the quality of life of persons with disabilities, and the implications of these programs and services for social work educators and practitioners. Specifically, this research offers empirical evidence to the usefulness of the human development model in the study of persons with mild intellectual disabilities; and its findings are appropriate for curriculum inclusion. The research methodology of understanding the person within a socially contextualized environment as well as the findings related to persons and their social environment complement the individual in the social environment perspective dominant in social work education. This research serves to raise the level of importance or status of understanding

persons with intellectual disabilities, and by extension, persons with developmental disabilities, within the social work profession. This concern for the professional regard for a service population is relevant to social work education and practice. The *Journal of Social Work Ethics*, devoted an issue (2008-2009) to issues related to social work and disabilities. In that issue, Hill and Lightfoot, (2008) noted that

there is clearly a need for more efforts to promote a positive image of disability among social workers. Providing specific training to social workers and other service providers on alternate, non-medical model perceptions of disability could begin to bring about a positive change in the way disability is perceived and understood. In particular, there is a need for social workers to have training on how to integrate a positive perception of disability within a strengths perspective practice approach. This training should be integrated into both academic and post-academic training, such as professional in-services or licensure trainings, and should not be limited to those in the field of disability services. (p. 14)

Russo-Gleicher (2008) reported that working with persons with developmental disabilities ranged the lowest of all social work client populations. She cited earlier confirming research (A. C. Butler, 1990; A. Rubin, & Johnson, P .J. , 1984; A. Rubin, Johnson, & DeWeaver, 1986). Russo-Gleicher investigated aspects of MSW experiences in the field of disabilities and claimed that there was little student interest in working with persons with disabilities. Her study results included a criticism from social work students that there was a lack of content on developmental disabilities in the classroom and a scarcity of internship opportunities. She claimed an excellent fit for social work with the developmental disabilities field; both placing high value on dignity, self-determination, and a strengths based approach, where capacity and potential are emphasized.

Russo-Gleicher found that social workers once employed in the field of disabilities, enjoyed their jobs and wished to stay in the field. DeWeaver (1980) as cited in Russo-Gleicher (2008, p. 145) found a similar result. Russo-Gleicher recommended that schools of social work include content on working with developmental disabilities in all courses, using role-play and case studies and to link theories, such as strengths theory, to working with this population. However, she did not take issue that the individual focus on persons with disabilities, remained

in the medical model. Nor did she include advocacy as a primary role for social workers working with persons with disabilities.

Social Work Practice

In recent years, the National Association of Social Workers (NASW) has moved toward the recognition of disability from a diversity perspective and moved away from a medical diagnostic perspective. (Stoesen, 2003) Depoy and Gilson (2008) argued that “social work had not attended to disability as a category of oppression, but rather had ministered to ‘people with disabilities’ through the provision of clinical services”; thus pathologizing the individual.

This research confirms the diversity perspective presenting disability as an influence similar to the influence of other diversity characteristics, such as race, ethnicity, and gender. Employing this approach elevates social work practice and policy to considering macro level characteristics related to discrimination and structural barriers.

The principles which underlie McAdams’ theory of human development, i.e. that individuals strive to live a life with purpose and unity are compatible with social work practice. The research findings provide clinicians with the knowledge that persons with mild intellectual disabilities generate their desires and actions from the same base of desires and actions of all individuals. Clinical protocols should include assessments and interventions that address developmental goals used in the at large population.

This research supports Murphy and Pardeck’s (2005) recommendation that Clinically, a range of vital social variables should be part of any assessment or intervention. Every effort must be made so that persons who are formerly marginalized are heard and treated equitably. Practice and philosophy should reflect that diversity is an asset. As a result, perhaps novel opinions and intervention strategies will begin to be recognized as viable.” (p. 168)

Additionally, the findings are consistent with Murphy’s and Pardeck’s statement that “instead of trying to normalize persons, interventions should be constructed that address how they can create meaningful lives for themselves” (p. 167).

Rothman (2003) in her text, *Social Work Practice Across Disability*, cited the NASW’s Code of Ethics regarding the belief in the client’s capacity to change, worthiness, empathy, patience and understanding and calls upon the social worker to use communication skills that

establishes trust and relationship. She stated that during the assessment process the social worker needs to understand the client's experience as a subjective reality, from a strengths based perspective and to see the person as more than the medically based criteria of quality of life issues.

These findings support social work's commitment to empower the individual and the group. The findings lend evidence that highly generative persons often lead and participate in advocacy-oriented activities and possess a strong sense of agency. Social work practice can advocate for strengthening the current person centered practice, such as the individual waiver options, in the significant life areas of employment, housing, and support care. Advocacy can occur at any level, micro, mezzo and macro. Social work research, using a mixed method approach, can produce a body of knowledge that captures the individuality of persons with mild intellectual disabilities, explores the similarities and differences within groups of persons with mild intellectual disabilities, and allows for the integration of such research into the larger body of human development and life story research.

Implications of Research for the Field of Disability Study

Disability study scholars (Develieger & Trach, 1999; Goodley, 2003; Rolph, 2000; S. J. Taylor, 2000; Whitney-Thomas & Moloney, 2001) have used the life story methodology to explore the lives of persons with intellectual disability. However, this methodology typically preferences the theoretical framework of stigma and consequently the research questions, and not surprisingly, the findings focus on differences of persons with intellectual disabilities rather than the possibility of likenesses in humankind. This research raises the question and adds empirical findings to how we are more alike than different. Differences are found within the sample of individuals with intellectual disabilities rather than in contrast to the population at large. By asking the question differently- how are we more alike than different- we begin to broaden the conversation.

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Appendix A

Life Story Interview-Adapted

Let's imagine that you are going to make a movie about the story of your life. As a researcher, I am interested in hearing your story. You can't put everything that has happened in your life in this movie, but only parts of it and you can decide what to put it. There are no right or wrong answers. This is about you and what you remember and think your life. I will ask you some questions and we will probably talk for about an hour. If we need more time we can make another time together. Remember everything that you say is voluntary, you don't have to tell me and I will not share your story using your name, it is confidential. Do you have any questions about this? Remember I am using a tape recorder to help me remember and think about all that you tell me. Ready?

A. General Plot and Title

1. If you were making a movie about your life, tell me briefly what it would be about?
2. And what would the name of the movie be?

B. Key Scenes

Now that you have the name of the movie, I want to know about the important scenes in your life movie.

We will talk about nine scenes or parts of the movie: who is in the scene, what exactly happens, what you are thinking or feeling about the scene and what you think this scene might say about you. I will ask you these questions again if you need me to, as we go along.

Ready? First is the

1. High point scene: this is about a great happiness; it is the best scene in the movie. Tell me about it, What does this scene say about you as a person?(Interviewer will ask about details as needed as described above)

Now let's talk about the another scene; this is the

2. Low point scene. This is the worst scene of the movie. What is it about? What does this scene say about you as a person? (Interviewer will ask about details as needed as described above)

Okay, now let's go to the

3. Turning point scene... This scene is where you experience an important life change, something that changed your life. Tell me about it. What does this scene say about you as a person? (Interviewer will ask about details as needed as described above)

Okay, now for the next one, we are on number four. We have five more to go. Tell me about

4. Earliest memory scene This scene is about your earliest memory, what is it about? Is it a positive or negative memory? What does this scene say about you as a person? (Interviewer will ask about details as needed as described above)

The next scene is the

5. Important childhood scene. This scene will show something important to you in your childhood, from a baby until you are a teenager. Tell me what would it look like? What does this scene say about you as a person? (Interviewer will ask about details as needed as described above)

Now for scene six.

6. Let's talk about an important scene where you are a teenager. (Adolescent scene) Tell me about the scene. What does this scene say about you as a person? (Interviewer will ask about details as needed as described above)

Great, can you guess the next scene? It's the

7. Important adult scene. This scene should not be a repeat of any of the other scenes, but a new one that tells me something about your adult life and who you are. Tell me what this

scene would be about, what do you want the scene to show in your adult life?
(Interviewer will ask about details as needed as described above)

8. Wisdom scene Describe a scene in which you showed wisdom. You may have done something that was wise, in using your judgment or making a good or bad decision or giving wise advise Tell me about this scene, what does it say about you?
9. The last scene is about a religious or spiritual experience. It doesn't matter if you go to church or not. This is a scene that says something about you and God or someone or something else that you believe. Think about your entire life and tell me about a memory or scene that shows a spiritual or religious part of your life. If you can do this, what would it look like?

Now that we have the scenes, let's talk a little more about the important characters in the movie. Who or what has been important to you. First, let's talk about

C. Characters

1. Characters and you can think about this as a person or an institution. An institution might be like a school, a church, an organization, some place where you go that is important to you. Can you give me an example of an institution?
 - a. Describe who or what has had the most positive influence or impact on your story, in your movie?
 - b. Who or what has had the most negative influence on your story? Tell me about this important person (institution)

D. Life Challenges

1. Okay now let's think about, life challenges, things that have been hard for you or things that you have had to face. If you were telling your life as a movie, what would be the single most greatest or biggest challenge for you? (Interviewer will ask about details as needed as described above) Now think about the next movie that you would make about your life.

E. Future Script/Life Theme

1. What would this movie look like? (Future plot) What happens next in your life? What goals do you have? How do you want the movie to end? Great, now let's talk about the theme, or the message that goes through your life.
2. What would you say is the moral of the movie or the life theme in your movie? If you could make this movie and people would see it, what would they say the movie is about?

Okay let's talk about a few more things, that are not part of making a movie but still are important things to know about you. So we put the movie idea away.

3. Favorite stories or movies? What are they; tell me about them, what do you like about them?

Now I'm going to ask you about your values and beliefs? Do you know what is a value is? What is a belief? (If interviewee understands, interview moves ahead. If there is a difficulty in understanding, the interviewer will define values and beliefs as: *these are what you think are important in how one lives, these are what you believe in*. An example of a value or belief is "I believe that all Americans should vote", or "I believe that everyone should be treated with respect.", or "I think everyone has a right to go to the church that he/she wants to go to". Can you give an example of a belief?

F. Personal Ideology/Values

1. Religious/ethical values: Think about the religious or spiritual part of your life. Describe to me, your religious beliefs and values. If you are not religious, describe to me the rules that you live by, how you know that you or someone else is a good person. And when you think about your beliefs, how have you lived by them?
2. Political/social values: Do you have a particular political viewpoint? Are there causes or ideas that you feel strongly about? Please tell me about them. And when you think about what beliefs or values are important to you, how have you lived by them?
3. Change, development of religious and political views: Please tell me how you came to believe in what you believe in today. How did these ideas and values come about?

Who influenced you? Have they changed over time? If so, how have they changed?
How have you acted differently as your beliefs have changed?

4. Single Value: What is the most important value in living? Please explain.
5. Other: What else can you tell me about yourself , that might explain how you live and think and feel today?

G. Reflection

1. Thank you for talking to me. You know that we talked about some very important things today and I'm wondering how this has been for you to talk about these things. How this interview affected you? Now we will go onto to a few more other things, are you ready? If interviewee says yes, we proceed, if not we take a break, and if needed schedule another time.

Based on Dan P. McAdams The Life Story Interview

The Foley Center for the Study of Lives

Northwestern University

Revised Feb. 2008

Some questions included earlier versions of The Life Story Interview

Revised for purposes of current research 11/22/2010

Appendix B

Satisfaction with Life Scale

Instructions:

Below are five statements with which you may agree or disagree. Using the 1-5 scale below, tell me your agreement with each item You will rate your agreement from 1 to 5, and I will mark the number that you tell me.

Please be open and honest when you answer.

The 5 point scale is

1=Strongly disagree, 2=Disagree, 3=Neither agree nor disagree, 4=Agree, 5= Strongly agree.

Remember how we talked about this before, with the numbers?

Items

1. In most ways my life is close to ideal.
2. The conditions of my life are excellent.
3. I am satisfied with my life.
4. So far I have gotten the important things I want in life.
5. If I could live my life over, I would change almost nothing.

(Diener, Emmons, Larsen, Griffin, 1985)-Adapted to a 1-5 Scale for purposes of current research

Appendix C (a)

Loyola Generativity Scale (LGS)

Retrieved from <http://www.sesp.northwestern.edu/foley/instruments/lgs/>

Instructions

For the interviewer: Mark "0" if the statement never applies to person. .

Mark "1" if the statement only occasionally or seldom applies to person. .

Mark "2" if the statement applies to the person fairly often.

Mark "3" if the statement applies to the person you very often or nearly always.

___1. I try to pass along the knowledge I have gained through my experiences

Note:

___2. I do not feel that other people need me.

Note:

___3. I think I would like the work of a teacher.

Note:

___4. I feel as though I have made a difference to many people.

Note:

___5. I do not volunteer to work for a charity

Note:

___6. I have made and created things that have had an impact on other people.

Note:

___7. I try to be creative in most things that I do.

Note:

___8. I think that I will be remembered for a long time after I die.

Note:

___9. I believe that society cannot be responsible for providing food and shelter for all homeless people.

Note:

___10. Others would say that I have made unique contributions to society.

Note:

___11. If I were unable to have children of my own, I would like to adopt children. Note:

___12. I have important skills that I try to teach others

Note:

___ 13. I feel that I have done nothing that will survive after I die.

Note:

___ 14. In general, my actions do not have a positive effect on other people.

Note:

___ 15. I feel as though I have done nothing of worth to contribute to others.

Note:

___ 16. I have made many commitments to many different kinds of people, groups, and activities in my life.

Note:

___ 17. Other people say that I am a very productive person.

Note:

___ 18. I have a responsibility to improve the neighborhood in which I live.

Note:

___ 19. People come to me for advice.

Note:

___ 20. I feel as though my contributions will exist after I die

Note:

Appendix C (b)

Loyola Generativity Scale (LGS)

Retrieved from <http://www.sesp.northwestern.edu/foley/instruments/lgs/>

Adapted for dissertation purposes 2/23/2010

Instructions

The interviewer will read the following and mark as interviewee indicates.

If you have done one of these, try to remember how many times. I will ask you how many times you have done each behavior, or if you never did this. You have probably done some of these and there are some that you haven't done. I will read each one of them, and please tell if you have done this since

For the interviewer: Mark "0" if the statement never applies to person. .

Mark "1" if the statement only occasionally or seldom applies to person. .

Mark "2" if the statement applies to the person fairly often.

Mark "3" if the statement applies to the person you very often or nearly always.

Note: The italicized statements are adapted statements for purposes of this research.

___1. I try to pass along the knowledge I have gained through my experiences. I try to pass on what I know. I try to tell others about what I know through my experiences.

Note:

___2. I do not feel that other people need me.

Note:

___3. I think that I would like to do what a teacher does.

Note:

___4. I feel that I make a difference to many people; I feel that I am important to many people.

Note:

___5. I do not volunteer.

Note:

___6. I have made things that other people appreciate, like or feel drawn to.

Note:

___7. I try to be creative in most things that I do.

Note:

___8. I think that I will be remembered for a long time after I die.

Note:

___9.. I believe that we should give food and shelter to all homeless people. –

Note:

___10. People would say that I have done something special for society, for others.

Note:

___11.If I can't have children of my own, I would like to adopt children.

Note:

___12. I have something important that I try to teach others.

Note:

___13. I feel that people won't remember me after I die, that there isn't anything that I did that people will remember.

Note:

___14. I could say, that what I do doesn't have a good/positive effect on other people.

Note:

___15. I feel that I haven't done anything good for others. I feel that I haven't contributed anything to other people.

Note:

___16. I have made many promises to do things for many different kinds of people, groups in my life.

Note:

___17. Other people would say that I keep busy in a good way.

Note:

___18. I have a responsibility to improve the neighborhood in which I live.

Note:

___19. People come to me for advice.

Note:

___20. I feel that after I die, what I have done in this world will live on.

Note:

Appendix D

Adapted : Generative Behavior Checklist (GBC)

Retrieved from: <http://www.sesp.northwestern.edu/foley/instruments/gbc/>

Instructions

Adapted for dissertation purposes.

Below is a list of specific behaviors or acts. Over the past two months, it is likely that you may have performed some of these behaviors. It is also likely that you have not performed many of them as well during this time. Please consider each behavior to determine whether or not you have performed the behavior during the past two months. If you have performed the behavior, please try to determine how many times you have performed it during the past two months. For each behavior, provide one of the following ratings:

The interviewer will read the following and mark as interviewee indicates

"0" in the blank before the behavior if you have not performed the behavior during the past two months.

"1" in the blank if you have performed the behavior one time during the past two months.

"2" in the blank if you have performed the behavior more than once during the past two months.

Have you:

- ___ 1. Taught somebody a skill.
- ___ 2. Served as a role model for a young person.
- ___ 3. Won an award or contest.
- ___ 4. Went to see a movie or play.
- ___ 5. Gave money to a charity.
- ___ 6. Did volunteer work for a charity.
- ___ 7. Listened to a person tell me his or her personal problems.
- ___ 8. Purchased a new car or major appliance (e.g., dishwasher, television set).
- ___ 9. Taught Sunday School or provided similar religious instruction.

- ___ 10. Taught somebody about right and wrong, good and bad.
- ___ 11. Told somebody about my own childhood.
- ___ 12. Read a story to a child.
- ___ 13. Babysat for somebody else's children.
- ___ 14. Participated in an athletic sport.
- ___ 15. Gave clothing or personal belongings to a not-for-profit organization (such as the "Good Will," "Salvation Army," etc.).
- ___ 16. Was elected or promoted to a leadership position.
- ___ 17. Made a decision that influenced many people.
- ___ 18. Ate dinner at a restaurant.
- ___ 19. Produced a piece of art or craft (such as pottery, quilt, woodwork, painting, etc).
- ___ 20. Produced a plan for an organization or group outside my own family.
- ___ 21. Visited a nonfamily in a hospital or nursing home.
- ___ 22. Read a novel (optional if indicated that person reads).
- ___ 23. Made something for somebody and then gave it to them.
- ___ 24. Drew upon my past experiences to help a person adjust to a situation.
- ___ 25. Picked up garbage or trash off the street or some other area that is not my property.
- ___ 26. Gave a stranger directions on how to get somewhere.
- ___ 27. Attended a community or neighborhood meeting.
- ___ 28. Wrote a poem or story.
- ___ 29. Took in a pet.
- ___ 30. Did something that other people considered to be unique and important.
- ___ 31. Attended a meeting or activity at a church (not including conventional worship service such as Mass, Sunday morning service, etc.).
- ___ 32. Offered physical help to a friend or acquaintance (e.g., helped them move, fix a car, etc.).
- ___ 33. Had an argument with a friend or family member.
- ___ 34. Contributed time or money to a political or social cause.

- ___ 35. Planted or tended a garden, tree, flower, or other plant.
- ___ 36. Wrote a letter to a newspaper, magazine, Congressman, etc. about a social issue.
- ___ 37. Cooked a meal for friends (nonfamily members).
- ___ 38. Donated blood.
- ___ 39. Took prescription medicine.
- ___ 40. Sewed or mended a garment or other object.
- ___ 41. Restored or rehabbed a house, part of a house, a piece of furniture, etc.
- ___ 42. Assembled or repaired a child's toy.
- ___ 43. Voted for a political candidate or some other elected position.
- ___ 44. Invented something.
- ___ 45. Provided first aid or other medical attention.
- ___ 46. Attended a party.
- ___ 47. Took an afternoon nap.
- ___ 48. Participated in or attended a benefit or fund-raiser.
- ___ 49. Learned a new skill (e.g., computer language, musical instrument, welding, etc.).
- ___ 50. Became a parent (had a child, adopted a child, or became a foster parent).

Appendix E

Coding Systems for Themes of Agency and Communion

Retrieved from <http://www.sesp.northwestern.edu/foley/instruments/agency/>
2/23/2010

Dan P. McAdams

(With assistance from Bonnie Kaplan, Mary Anne Machado and Yi Ting Huang)

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Revised: October 17, 2002 David Bakan (1966) introduced the concepts of agency and communion in the following passage:

I have adopted the terms "agency" and "communion" to characterize two fundamental modalities in the existence of living forms, agency for the existence of an organism as an individual, and communion for the participation of the individual in some larger organism of which the individual is a part. Agency manifests itself in self-protection, self-assertion, and self-expansion; communion manifests itself in the sense of being at one with other organisms. Agency manifests itself in the formation of separations; communion in the lack of separations. Agency manifests itself in isolation, alienation, and aloneness; communion in contact, openness, and union. Agency manifests itself in the urge to master; communion in noncontractual cooperation. (pp. 14-15).

These two generic "modalities in the existence of living forms" may also be viewed as two thematic clusterings in life narratives, each articulating important life goals, strivings, needs, and desires. Following the work of Bakan and many others, McAdams (1985; McAdams, Hoffman, Mansfield, & Day, 1996) has suggested that agency and communion are the two central superordinate thematic clusters in life narratives. People's life stories differ with respect to the salience of agency and communion themes, and those differences are measurable. This manual is designed to enable the researcher to capture some of those individual differences in the thematic coding of particular life narrative episodes. It describes a simple and reliable method for coding the salience of agency and communion themes in written or verbal accounts of especially significant autobiographical events, or what McAdams (1985) calls "nuclear episodes" in life

stories.

The coding system is designed to detect the salience of agency and communion themes in accounts of discrete life-story episodes, such as life story "high points," "low points," "turning points," and "earliest memories." Such accounts may be collected through life-narrative open-ended questionnaires or through interviews. In general, the coding scheme works best when subjects describe particular events in their lives that they find to be especially personally meaningful -- events that the subjects themselves may see as having had an important impact on their identity. For each event, subjects are typically asked to describe (verbally or in writing) what happened in the event itself, who was involved, what the subject was thinking and feeling during the event, and what (if anything) the event means in the context of the subject's own self-defining life story. Subjects may describe events that are either positive or negative in emotional tone. In general, however, the categories described below refer to positively-valenced themes in life narrative.

In coding an account for themes of agency and communion, the scoring unit is the episode itself. Each episode is coded for the presence (score +1) or absence (score 0) of eight different themes, four under the heading of agency and four under the heading of communion.

The four agency themes are: (1) Achievement/Responsibility (AR), (2) Power/Impact (PI), (3) Self-insight (SI), and (4) Status/Victory (SV). The four communion themes are: (5) Love/Friendship, (6) Dialogue (DG), (7) Caring/Help (CH), and (8) Unity/Togetherness (UT). The coder must determine whether or not the story contains evidence of each of the eight themes. If evidence exists for the theme in the episode, then the theme receives a score of +1 for the corresponding episode. If no evidence exists, the theme receives a score of 0 for that episode. A theme is scored only once per episode. Theme scores may then be summed across agency and across communion categories within an episode, to provide summary scores for agency and communion respectively. Thus, the highest possible score for agency or communion for a given episode would be "4." The lowest score would be "0."

The coding system for agency and communion is a conservative scheme. The scorer should not give a point (+1) for a given theme in a given episode unless there is clear and explicit proof of the theme's existence in the episode. The scorer should be careful not to read anything into the literal description of the account. The scorer should avoid clinical inferences and extensions beyond the written or spoken word.

Two independent coders should score episodes, and then correlation coefficients should be calculated to determine interscorer reliability. Reliabilities may be calculated for each theme score, summed across however many episodes a subject describes, and for the total agency and total communion scores, summed across episodes. Scorers may need to work together in early phases of coding in order to build up a common understanding, so that eventually their independent codings will show acceptable reliability. Themes of Agency

Agency encompasses a wide range of psychological and motivational ideas, including the concepts of strength, power, expansion, mastery, control, dominance, autonomy, separation, and independence. Most accounts of important autobiographical experiences are couched in agentic terms to one degree or another. After all, the subject is telling the researcher about an important experience for the self, so we should not be surprised if the account entails at least a modicum of self-celebration, self-focus, self-expansion, and so on. The necessary focus on the self, therefore, encourages a rhetoric of agency in most autobiographical accounts, especially among contemporary citizens of Western societies, imbued with an ethic of individualism. For example, many turning point episodes will tell how a person moved from dependence to "autonomy." The attainment of autonomy in human development is a very common theme among Westerners, especially those in the middle classes. The four agentic themes articulated below, however, go above and beyond the typical agentic rhetoric of autobiographical expression. They express highly agentic ideas that, even by the cultural standards of contemporary self-rhetoric, stand out as especially indicative of Bakan's concept of agency in human lives.

1. ACHIEVEMENT/RESPONSIBILITY (AR).

The protagonist in the story reports substantial success in the achievement of tasks, jobs,

instrumental goals, or in the assumption of important responsibilities. He or she feels proud, confident, masterful, accomplished, or successful in (1) meeting significant challenges or overcoming important obstacles concerning instrumental achievement in life and/or (2) taking on major responsibilities for other people and assuming roles that require the person to be in charge of things or people. Most often these accomplishments and responsibilities would occur in achievement settings, such as school or work, rather than in more personal settings, such as with reference to spiritual or romantic goals. This category requires that the protagonist strive to do things, produce things, or assume responsibilities in such a way as to meet an implicit or explicit standard of excellence. In this sense, AR bears strong resemblance to the "achievement motivation" scoring categories in McClelland and Atkinson's coding system for TAT stories (McClelland et al., 1953).

Examples of AR:

A student works hard to perfect a short story for a class assignment. He spends hours polishing word choice, getting the imagery right, and so on.

An executive meets his annual goals for the company.

A young boy builds a tree house, and he is very proud of his accomplishment.

A student masters a class on computer programming.

A secretary takes over an office and turns it into a model of efficiency and productivity.

After having their first child, a couple now realizes the significant financial responsibilities they have assumed.

A woman endeavors to interact with her colleagues in a "healthy and productive manner." Here the explicit reference to being productive in the workplace qualifies the response for AR.

A woman describes her movement from college to graduate school: "I was able to settle down and become focused and to become productive in a much more real way than up until then. I had always produced a lot of stuff academically; I'm also the kind of person who is constantly productive with something, or at least I used to be that way. I would have six projects going on at once." But now she was able to become more focused on one project at a time, which enhanced her productivity.

A father reflects: "You're the head of the family and you're responsible for a lot more than you

were before. It's a real maturing experience."

A group of young adults builds a community in the wilderness: "We were building a community. We were really working with our muscles, you know, passing buckets of cement."

A man is accustomed to failing, but he achieves success in an important business venture, building his confidence.

An author publishes her first short story.

A middle-aged mother reflects on her children, who have recently left for college. She decides that she has done an "excellent job" as a caregiver. Even though this is an interpersonal rather than instrumental task, the writer explicitly couches it in achievement terms -- as a job well done.

A pilot completes his first solo flight.

Studying a foreign culture for many years, an anthropologist comes up with a new way of seeing the culture, solving an intellectual problem which she had puzzled over for a long time.

First day on the job, a nurse confronts a difficult assignment, but she is successful in completing the task.

At the age of 65, a man runs in his first marathon.

A young man is kicked out of his house by his parents. He struggles to survive, but eventually he becomes "a successful and responsible adult."

A woman is proud of her college achievements -- in academics as well as in clubs and associations on campus.

A man reports after his divorce: "I challenge myself to the limit academically, physically, and on my job. Since that time I have accomplished virtually any goal I set for myself. I have never been happier."

A woman reports after her divorce: "In order to survive financially and support these children, I decided to enroll in a graduate program in counseling psychology at a major university. I was accepted and began the program with great determination . . . I felt the failure of marriage was reversed by the success of completing a graduate degree through years of difficult and intellectually stimulating study."

"This was my senior recital. I began my first piece. I played it with all my heart. I never felt so proud of myself before. I wanted to do a terrific job and I did."

"My important goal is finding a job. I just went to my first interview. I managed to calm myself

down and answer the question professionally. In general, the experience was pretty positive and will help in future interviews."

"Right now the single most important goal to me is getting into medical school. In the summer, I voluntarily joined an apprenticeship program where I was to help out and learn at the hospital in the surgery department. If I had not finished the program, I would not have something to submit to the medical schools, showing them what I did."

"The earliest memory I have is the day I first dressed myself. It was a huge accomplishment for me because I did something on my own that I always needed help for."

I chose to come to this university over others, and I chose to work hard and enter a competitive environment rather than enter a school where I could have more fun and work less."

"I remember learning how to ride a bike at age seven."

"One of my goals is to get involved in the deaf community and increase my sign language proficiency. Last year I was taking my first American Sign Language classes. A year later, I am conversing with people by signing in front of a group."

"My freshman and sophomore year were very tough academically. So I took biology the summer after my sophomore year and it actually went okay. This was the summer when I learned how to study."

"Every Saturday of home game the marching band performs a highly demanding thirteen minute show that requires us to push ourselves to our limits. I loved the performance exhilaration and constantly challenging myself to perform better than before – to push my limits and grow as an individual."

"The birth of my younger brother was a new addition to our family. I was no longer the youngest child. It was my turn to carry some responsibility."

"When I was three, I was lying on the floor of our kitchen writing my name with a red crayon. I learned how to read and write at an early age."

"I think winning the 1990 Golden Apple Award for Excellence in Teaching was my high point because I was the one who accomplished it."

"A turning point occurred for me in 1984 when my daughter was born. I then realized that becoming a father was a huge responsibility and took a lot of work and patience."

"The day I graduated from graduate school was a very special day in my life...I felt very excited and proud to have finished my degree...I took a risk to go back to school and I did it."

2. POWER/IMPACT (PI).

The protagonist asserts him- or herself in a powerful way and thereby has a strong impact on other people or on the world more generally. The impact may take the form of aggression (physical or verbal), retaliation, argument, persuasion, control, or attempting to make a strong impression on others. The protagonist feels strong, masterful, powerful, or especially effective in exerting his or her will to change things in the environment. The change may be destructive or positive. Positive change may come from leadership or other effective actions that mobilize people to do things in accord with the wishes or plans of the protagonist. This category resembles the "power imagery" prime category in the TAT-based scoring system for power motivation (Winter, 1973).

Examples of PI:

A politician pushes through a piece of legislation.

A woman persuades her friends to change their views about a controversial topic.

A graduate student impresses her advisor.

A bully beats up other children on the playground.

A woman slaps her husband.

Somebody saves somebody else's life.

A preacher's sermon is so convincing that many people in the congregation go through a conversion experience.

The lawyer convinces his client to accept the terms offered by opposing counsel.

"I had a toy my friend wanted, but I had it first so she bit me and took the toy. I bit her back."

"I was a lifeguard during the summer. As I was looking around the pool sitting in my chair, I suddenly notices an overturned raft with a little boy struggling next to it. I just quickly jumped in the water, grabbed the kid within a couple of seconds, and gave the kid to his father."

"My family was pressuring me and I was not feeling happy or capable of emotional stability. I

somehow ended up getting into an argument with my brother and mom and bursting into tears and shaking all the while saying, 'Look if you guys don't back off and stop pressuring me, I'm going to go nuts and you're going to have to pay for a psychiatrist.' I think they realized that I put enough pressure on myself without their added help."

"My good friend got alcohol poisoning. I took charge of the situation and took her to the emergency room."

"I am a woman of convictions who needs to feel as independent as possible. Accordingly, I began to feel hampered by my boyfriend's expressions of love. I decided to break up with him. This incident shows that I can be assertive and will do what is best for me no matter how much it hurts."

"I went out on my first real date when I was sixteen years old. I remember my grandmother being really strict and saying that I could not go out with anyone. But I rebelled and sneaked out of the house at night when my grandmother was asleep to date this guy."

"As we were leaving the bar, one of my girlfriends was being harassed by an intoxicated male. In an effort to defend her, me and several of my fraternity brothers spoke up and thus started a fight."

"There was alcohol at this party and almost everyone was becoming rather intoxicated. Even though I knew I would be made fun of, I refused to let any of my friends drive home."

"I find it important to set a positive first impression to people who have never met a Jew. There are moments when it is harder but in general all of these experiences have made me realize that it is important to do everything in my power to change myself and therefore influence others."

"Moving to college was a very high point in my life. This was the first time in my life I was going to be on my own and that gave me a great joy. I knew that the homesickness would go away because I was strong and was going to make it on my own."

"I took part in a show where I was in one of the dance numbers. I always wanted to do it my way. I have been like that for as long as I can remember. I am very high in power motivation. I like being in charge or in control. When I am not, it bothers me and I react against those who are."

"I remember walking home from first grade with my brother. He told me 'there is no such thing as Santa Claus, the Easter Bunny, and the Tooth Fairy.' I was devastated – but I wasn't a

crybaby so I didn't tell my mom and instead I went to school the next day and told everyone else. If my childhood was going to be ruined, I decided everyone else's should be."

"In eighth grade, I got in a huge fight with a bully that had given me a hard time for a couple of years. But this day he kept pushing all my buttons so I picked a fight. He had beaten me down long enough so I took control of the situation. He didn't pick on me anymore because I had shown him up in front of a bunch of people."

"I attended an international peace conference in Venice, Italy. I realized how many other young people like myself wanted to affect change in their community."

"I am glad my eyes were opened early to the fact that there were a lot of prejudiced people in my class. Later in junior high, I would break out of my usual silence when people would make racist remarks in class or tell a racist joke. It was at this point that I would speak out and try to make people realize they were wrong."

"When we agreed to pledge a fraternity, most of us expected some sort of hazing to come along with it. One night, the fun was pushed to its limits. I decided something needed to be done. The next day, I called the national headquarters. For the first time, I stood up for what I believed in."

"...I told him I would make up a bed in the living room and that he was to leave the next day...Ever since then I've had increasing confidence in my capabilities...I really believe this comes from an inner strength which some find in religion but I think I find in myself."

"I was always defending my mother and raging against (my father) and his drinking."

"I see this event as the first time that I can remember directly questioning and confronting authority with logic and reason...I now feel that this event had a strong bearing relative to my view of authority which does not like to be questioned...Never again would I allow any authority over me to go unexamined."

3. SELF-INSIGHT (SI).

The story protagonist attains a clear, new, and important insight about him or herself through the event. As a result of this experience, the protagonist feels that he or she has become wiser, more mature, or more fully actualized as a person. The insight may be seen as a transformation in self-awareness or a leap forward in self-understanding that entails the realization of new goals, plans,

or missions in life -- a significant insight into one's identity.

Examples of SI:

A woman comes to see her life's mission as being an artist. She quits her job, sets up a studio, and strives to actualize her dream. (also scores for AR.)

A young man experiences a religious conversion which provides him with new insight into his own life.

A middle-aged man realizes that he is being exploited by his current employer. He breaks away from the firm and embarks upon a new line of work, more in keeping with his life goals.

A woman comes to the conclusion that she has wasted 20 years of her life in a desperate drive for material well-being. She decides to dedicate her life to helping others.

Inspired by reading Freud, a young man comes to the realization that he wants to be a psychotherapist.

After a near-death experience, a man comes to a new understanding of the quality of life. He pledges to slow down, enjoy his family more, take everything one day at a time.

After the death of his son, a man changes his "philosophy of life."

"I had a series of meaningless college relationships until I realized it was better to be in no relationship than in a bad meaningless one."

"Being here for two years, I definitely feel that I have grown as a person and am in the process of establishing an identity of what kind of person I am."

"For a long time, I had planned on being pre-med. The first day of my first chemistry exam, I was near failure. I felt at that time that I had known what I wanted to do with my life, but after that test I realized it was something I had made up."

"I had been struggling with manic depression. I prayed to God, telling Him about my misery. I opened my Bible to John 4, read it and not only saw myself but the Savior who loved me and was able to fill the void in my life. I've never been the same since that day. God showed me that He wanted to give me a brand new identity that wouldn't condemn me."

"One afternoon, as we were walking through a park, we saw a couple of children playing. I realized that afternoon that I wanted to have children and a family more than anything else in

life. Talking with relatives who were doctors, I began to understand how much different reality would be from the dream I had if I were to become a doctor. I learned that I valued family more than money, prestige, or any other possession I may have."

"The day of my dad's funeral, I looked out into the crowd and realized just how full the church was. Everyone I knew was there and hundreds I didn't. I was completely awed and it was then that I realized that I never really knew my father. My perspectives on life, faith, and family were never to be the same."

"...I became conscious, I feel, for the first time, that the price of loving so completely, so unconditionally, is that...I would feel excruciating pain if she were to die or be separated from me forever. This event is significant because I felt so alive – so capable of being loving without consciousness about acceptance/non-acceptance and other self-centered thoughts."

"I realized then that I was capable of achieving anything I desired academically. I didn't have to accept as gospel truth the negative opinions of others concerning my abilities. From then on I knew I could fly and I did."

4. STATUS/VICTORY (SV).

The protagonist attains a heightened status or prestige among his or her peers, through receiving a special recognition or honor or winning a contest or competition. The implication in SV is that status or victory is achieved vis a vis others. There is always an interpersonal and implicitly competitive context in SV. Typically, the person "wins." There is victory or triumph. SV refers to significant recognition, especially prestigious honors, and various kinds of victories over others. Simply "doing a good job," getting good grades, or successfully achieving a goal is not enough to score for SV.

Examples of SV:

A young woman is elected homecoming queen.

An actor wins a coveted lead part in an upcoming play.

A student graduates from college with special honors (e.g., magna cum laude).

A person receives an award for outstanding achievement.

The quarterback completes a crucial pass, which gives his team the victory in the football game.

A musician receives a standing ovation.

A professor is honored at a party for receiving tenure at the university.

An aspiring writer is granted admission to a prestigious graduate program.

A swimmer wins a race.

A lawyer wins a case.

A person is granted an important position or awarded a prestigious job.

A high school student gains admission to a good university.

A student wins a scholarship or grant.

"I got accepted to the University of Pennsylvania. It was expensive but had a good reputation."

"One game we played a rival high school who is always a tough opponent. I saw the ball go into the corner of the net and the arms of all my teammates in the air and embracing me. We won the game. The game-winning goal made me feel proud and very good about myself."

"A peak experience occurred when I participated in the Martin W. Essex School for the gifted and talented. It was a summer program for sixty high school seniors who were selected based on academic excellence."

"My high school's varsity boys basketball team was in the finals of the state basketball tournament for the first time in the history of the school."

"The speech coach was finally able to convince me to attend the Iowa high school individual event speech contest my junior year. I presented a speech I had written for her speech class in the category of original oratory, earning the right to perform at the all-state speech festival.:

"In eighth grade I tried out for high school cheerleading and was one of the three girls from my class to make football and basketball cheerleading."

"Ten days ago, I swam what they call a perfect meet. I entered and won eleven individual events... Thus, I won the high point award, not only for my team but for the female of the entire meet."

"I was being presented with a little cup for "camper of the year" in my age group... I was singled out for something very special that meant people liked me."

Themes of Communion

Communion encompasses psychological and motivational ideas concerning love, friendship, intimacy, sharing, belonging, affiliation, merger, union, nurturance, and so on. At its heart, communion involves different people coming together in warm, close, caring, and communicative relationships. McAdams's (1980) thematic coding system for "intimacy motivation," employed with TAT stories, is explicitly modeled after Bakan's conception of communion, as well as related ideas in the writings of Maslow (being-love), Buber (the I-Thou relation), and Sullivan (the need for interpersonal intimacy). The four communion categories below represent a distillation and sharpening of the ten categories employed by McAdams in the TAT coding system for intimacy motivation. In addition, the four categories for communion draw more generally from Murray's (1938) communal concepts of "need for affiliation" and "need for nurturance."

5. LOVE/FRIENDSHIP (LF).

A protagonist experiences an enhancement of love or friendship toward another person. A relationship between people becomes warmer or closer.

Examples of LF:

Two friends feel that they grow emotionally closer to each other after spending time together on a vacation.

A man proposes to a woman. (Or vice versa.)

A woman describes her marriage to a wonderful man as the high point of her life.

A man marvels at the love and commitment his wife has given him over the past 40 years.

A young couple enjoy lovemaking on a Saturday afternoon.

An older woman teaches a young man about sex and love.

A woman is strongly attracted to a man in her class. He finally asks her out.

A couple reflects on their happy honeymoon.

A college student takes a friend to a formal dance: "I went to the formal with my friend, Melissa, even though she had a boyfriend. I felt incredibly happy during the slow dance with her. As I

held her close and tight, I felt her acceptance and happiness with me. We felt truly comfortable and happy with each other, as friends. Even though there was no direct romantic relationship between us, I sense a mutual true love."

A person remarks on a good friendship he has experienced.

"We spent the previous year building up a strong friendship at school in London."

"This simple phone conversation was the start of a new relationship with my mother."

"I value close relationships."

"This girl and I knew we liked each other. During our two weeks at camp, we carried on whatever semblance of a relationship 10-year-olds can carry on."

"I chose marriage and there have been illness-related complications. However, we will celebrate our 20th anniversary and I know I made the right decision. The quality of our relationship transcends the illness. Perhaps the illness has even brought us closer."

"...I befriended a priest...who was temporarily assigned to my parish. We were bonded together by our mutual love of music. We used to really 'hang out.'"

6. DIALOGUE (DG).

A character in the story experiences a reciprocal and noninstrumental form of communication or dialogue with another person or group of others. DG usually takes the form of a conversation between people. The conversation is viewed as an end in itself (justified for its own sake) rather than as a means to another end. Thus, such instrumental conversations as "interviews" or "planning sessions" do not qualify for DG because they are undertaken for noncommunal reasons (e.g., to obtain information or make plans). Furthermore, highly contentious or unpleasant conversations -- such as hostile arguments or exchanges in which people do not seem to be listening to each other -- do not qualify for DG. In order to score for DG, a conversation need not be about especially intimate topics, though of course it may be. A friendly chat about the weather, for example, would qualify for DG. What is important to note is that the communication between the protagonist and other characters in the story is reciprocal (mutual), nonhostile, and viewed as an end in itself rather than a means to an instrumental end. Note also,

that conversations for the express purpose of helping another person (e.g., providing advice, therapy) do qualify for this theme.

Examples of DG:

"We sat across from each other and tossed ideas back and forth, ideas of what we thought the plays were about."

"Sara and I had been writing letters to each other all summer."

"We drank a carafe of wine and had a memorable conversation about love and parents."

"My peak experience was both a time of sadness and joy. Sadness because my friend told me she had cancer. Joy because we had opened up to each other and it was a beautiful experience."

"My mother and I talked in depth about the problems my brother was having. I felt like so much of who I have become is like my mother. I felt warmth and closeness when we said good-bye."
(also scores for LF).

"On the last night, three of us plus or facilitators gathered around a circle with a single candle in the middle. We all went around to express our feelings of what peace was, what we learned from this unprecedented event . . ."

"When I was in preschool I recall sitting on my teacher's lap during a recess time and I remember her telling me . . ."

"I ran up the driveway into the house and picked up the phone. No one was home to share my moment with me, so I called my mom at work."

"My aunt had just had a baby girl, my cousin, and she asked me to be the godmother. I agreed without even thinking about what it meant to me."

"We had a great time, sitting around drinking wine after dinner and just talking into the night."
Sometimes a communication can be nonverbal, as in this example of DG: "She did not have to say a word. I knew instinctively what she meant."

7. CARING/HELP (CH).

The protagonist reports that he or she provides care, assistance, nurturance, help, aid, support, or therapy for another, providing for the physical, material, social, or emotional welfare or well-

being of the other. Instances of receiving such care from others also qualify for CH.

Examples of CH:

Many accounts of childbirth score for CH, as well as accounts of adoption. In order to score, the subject must express a strong emotional reactions of love, tenderness, care, nurturance, joy, warmth, or the like in response to the event.

Accounts of taking care of children as they grow up, meeting their needs and looking after them during difficult times, typically score for CH. Also included here are accounts of providing needed financial support, as in the role of the family breadwinner.

Providing assistance or care for spouses, siblings, parents, friends, co-workers, and colleagues may be included, as well. Mere technical assistance, however, does not qualify for CH. An emotional quality of caring must accompany the assistance, which is usually associated with providing counseling or therapy concerning life problems or interpersonal difficulties.

Developing empathy for other people, even if it is not acted upon in a given event, scores for CH. In one example, a woman describes reading a particular novel when she was a girl and developing an empathic attitude toward impoverished and oppressed people as a result.

"After I was sexually assaulted, my world was torn apart. The only thing that was stable in my life was the support I received from my mother."

"I like the feeling of being a vocal advocate and I would like to help others with similar problems."

"I held his hand to help him over the rocks safely."

"So I decided to have them settle their differences by taking them back to my room and for the next few hours, I had them talking and explaining each other's hatred, why there was miscommunications."

"My dad heard me and helped me. He helped me not only with the fly, but with my panic. He was caring, confident, and knew what to do."

"Near the end of 1967...a group of Black men decided to form an organization to help Black youth...My thinking at that time was, yes, there is a need to be a role model for our boys."

8. UNITY/TOGETHERNESS (UT).

Whereas the communal themes of LF, DG, and CH tend to specify particular relationships between the protagonist and one or a few other people, the theme of Unity/Togetherness captures the communal idea of being part of a larger community. In UT, the protagonist experiences a sense of oneness, unity, harmony, synchrony, togetherness, allegiance, belongingness, or solidarity with a group of people, a community, or even all of humankind. A common manifestation of this theme involves the protagonist's being surrounded by friends and family at an important event (e.g., a wedding, graduation), experiencing strong positive emotion because a community of important others have joined him or her at this time. However, there are many other manifestations of UT, as well.

Examples of UT:

"I was warm, surrounded by friends and positive regard that night. I felt unconditionally loved."

(Also scores for LF.)

Some accounts of weddings may qualify for both LF and UT. The developing love relationship between spouses provides evidence for LF while the wedding's bringing together of many friends and family members may provide evidence for UT.

Examples of being accepted, cherished, or affirmed by friendship, family, or other social groups qualify for UT.

"The most important part of the day was being surrounded by my peers who I loved . . . I finally felt completely comfortable with my classmates. I could call them my friends . . ." (Also scores for LF.)

"The bonds of sisterhood can never be broken. After a week and a half trampling around in the cold chitchatting for sorority rush, my Rho Chi Heather handed me the envelope and inside I saw it – the invitation to be a sister of Alpha Phi . . . What this says about my personality is that I love to belong . . ."

"This event showed me how much I cared for not only my dad but my mother and entire family as well."

"I remember when I joined the Cub Scouts...The uniforms that the scouts wore were blue. I couldn't wait until I received my uniform. It made me feel important and a part of something."

"We looked up and looming next to us, literally, was the Acropolis...I recall feeling both small and big in the sense of belonging to a society that was responsible for this tremendous architecture."

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Appendix F

Coding System for Redemption Sequences

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A redemption sequence is a particular narrative form that appears in some accounts of significant scenes in a person's life story. In a redemption sequence, a demonstrably "bad" or emotionally negative event or circumstance leads to a demonstrably "good" or emotionally positive outcome. The story plot moves from a negative to a positive valence, bad leads to good. Therefore, the initial negative state is "redeemed" or salvaged by the good that follows it.

Redemption is a common theme in both classic and contemporary narratives. In life story research, redemption sequences can be detected in a wide range of accounts that people provide, from their reconstructions of the past events, to their characterizations of what may happen in their lives in the future. The current coding scheme is based on research into the form and content of particular life-story scenes. A scene is a circumscribed event or episode in a life story, situated in time and place, and containing particular characters and action. In our research on life stories, we have focused mainly on the following kinds of scenes: life story "high points" (sometimes called "peak experiences"), life story "low points" (sometimes called "nadir experiences"), life story "turning points," "earliest memories," "significant childhood scenes," "significant adolescent scenes," "significant adult scenes," "decision scenes" (an episode in which the protagonist made a major life decision), "morality scenes" (an episode in which the protagonist confronted a moral dilemma), and a catch-all category that we call "significant other scenes" (in response to the question: "Describe one other important scene in your life story"). For each scene, the subject describes what happened, who was there, what he or she was thinking and feeling, and what the meaning of the scene might be in the context of his or her overall life story (e.g., "what does the scene say about who you are or who you were?"). These descriptions can be collected through life-story interviewing or through open-ended questionnaires in which

respondents write down or type out their accounts. Each narrated scene is coded as a whole. Thus, the coding unit for redemption sequences is the narrated account of one scene (e.g., a high point, a turning point, an earliest memory).

The coding scheme for redemption sequences is derived from theoretical writings on redemption scenes and commitment scripts (e.g., Carlson, 1988; McAdams, Diamond, de St. Aubin, & Mansfield, 1997; Tomkins, 1987) and the literature on posttraumatic growth (Tedeschi & Calhoun, 1995). The first literature frames an overall understanding of the movement from bad scenes to good scenes in stories, encoded in the category of "redemption imagery" described below. The second literature speaks to the positive aftermath or growth that may occur in an individual's life once a negative (even traumatic event) leads to a positive outcome, encoded in three subcategories for redemption sequences ("enhanced agency" "enhanced communion," and "ultimate concern") described below. In the overall, then, the redemption sequence coding scheme consists of four theoretically derived thematic categories:

1. Redemption imagery
2. Enhanced agency
3. Enhanced communion
4. Ultimate concerns.

The Prime Test: Redemption Imagery

In scoring a particular narrative account of an autobiographical scene for redemption, the coder must first determine the presence or absence of redemption imagery. If the scene contains redemption imagery, then it receives a score of +1, and the coder continues to look for the presence or absence of each of the three subcategories (enhanced agency, enhanced communion, ultimate concerns) in that particular scene. If the scene does not contain redemption imagery,

then it receives a score of 0 and no further subcategory scoring is done for that scene. Thus, if the scene scores 0 for redemption imagery, all redemption scoring of that scene ends, and the coder moves to the next scene.

The essential characteristic of redemption imagery is the movement in the story from a demonstrably negative to a demonstrably positive scene. We may call the negative or bad element of the sequence "A" and the positive or good element of the sequence "B". Thus:

A ---> B

The coder must first determine if there is a negative A state, scene, or situation in the account. Negative scenes are often described in terms of the protagonist's emotional state -- he or she may have felt fear, terror, sadness, grief, anguish, guilt, shame, humiliation, anger, distress, or any of a large number of explicitly negative affective states. Also relevant would be physical pain, injury, and sickness. In other cases, the author may not explicitly describe a negative feeling, but the event itself is an especially negative one -- e.g., death of a friend, divorce, major failure, poverty, addiction, broken relationship, being fired from one's job. The coder should consider a negative A state to be established if the respondent describes a scene in which he or she experienced significant negative affect or pain or if the respondent describes a scene that itself is so negative that it would most assuredly produce negative affect or pain for most any person experiencing it. The coder should be relatively conservative here. Minor setbacks (e.g., misplacing one's purse, waiting in line, getting a less-than-stellar grade on an exam) and mild negative states (e.g., feeling nervous at the beginning of a competitive event, feeling uncertain about one's skills, lacking direction in life) should not count for A. The event needs to be demonstrably negative. Especially negative scenes are often described in life story low points and turning points, but they can occasionally appear in most any kind of account, including even high points.

Once a negative A state has been determine, then the question of what, if anything, follows that

state must be asked. For redemption imagery to be scored, the negative A state must lead to an especially positive scene or state. Positive states are often indexed by positive emotions, such as feelings of joy, happiness, excitement, satisfaction, love, and the like. But they can also be indicated by certain especially positive cognitive results, such as increased understanding of self-insight, and by descriptions of events that themselves would likely elicit positive feelings in most people (e.g., close relationships, victory, reconciliation, healing, growth, learning). The positive state of B that follows the negative A state does not need to be as positive as the A state was negative. For example, the death of one's father is a very negative scene. The fact that the father's death ultimately led to an enhanced feeling of self-confidence on the part of the respondent is definitely a positive outcome (B), even though its strength or robustness is less, in absolute terms, than the death itself. Or to put it simply, a very dark cloud can still leave a faint silver lining, and such a sequence would score for redemption. Therefore, redemption sequences occur when some kind of positive outcome follows a negative event, even if that positive outcome pails in comparison to the intensity of the negative event. Still, the B state must be demonstrably positive. The author must explicitly describe a state that involves positive emotional or cognitive resolution, or one that is itself so positive as to produce such a result in most people. The coder should not make undue inferences about what the respondent means. The respondent needs to describe clearly a move from a negative A to a positive B.

The movement from A to B can take one of two forms. A may cause B (in the respondent's view) or A may merely immediately precede B in time.

In the first case, A leads to B by virtue of causation. A is the event or factor whose prior occurrence to B is the reason that B occurs. For instance, the death of one's spouse (A: bad) may cause a person to gain insight into his own life (B: good). Or a divorce (A) may eventuate in improvement of one's relationships with one's children (B). Or an especially painful delivery (A) produces a healthy baby (B). (Note the delivery did not have to be "painful" to eventuate in the baby, but the delivery itself still would be viewed as "causing" the baby to be born.) These events are constructed as causal narratives; B would not have occurred if A had not "caused" it.

In the second case, A need not cause B but merely precede B immediately in time. For example, a losing season (A: bad) is followed immediately by a championship season (B: good). Or a depressive episode (A) is followed immediately by winning the lottery (B). In these instances, the author is not trying to suggest that A caused B. Instead, A and B are juxtaposed in such a way that a very positive event follows on the heels of a very negative one. The link is temporal, but not necessarily causal. It is important to note that by "temporal," we are referring to chronological time in the plot of the narrative itself. B must follow A in the temporal scheme of the story. As an example of the contrary, consider a respondent who describes a bad experience in his life that occurred at age 30 and then proceeds to go back to incident in childhood that is contrastingly positive. Even though the positive event followed the negative one in the telling of the story, the positive event occurred in time long before the negative event occurred. Thus, such an account would not code for redemption imagery.

The content of A ---> B that makes up a redemptive sequence ranges widely. Common examples, though, fall into the categories of sacrifice, recovery, growth, learning, and improvement. Below are examples of each of these five common types ("S" designates subject):

1. Sacrifice. A character in the story willfully accepts or endures an extremely negative A in order to provide a benefit of B. Typically B is a benefit for another, though the self may also benefit. Thus, A is viewed as something of a sacrifice for the good inherent in B. Examples:

pain of delivery ---> birth of beautiful baby

difficult years working in a low-paying job ---> money saved enhanced child's education

S leaves husband because he wants her to have abortion, poverty ensues ---> joy of loving son

2. Recovery. The person successfully obtains a positive state again after losing it, as in healing, survival, regaining, recuperating, etc. Typically, A is a physical (injury, illness) or psychological (depression, trauma) condition and B is the healing outcome. Examples:

illness ---> cure

depression ---> regained positive outlook on life

near-fatal injuries ---> surprising recovery

alcoholism ---> successful treatment

severe anorexia ---> therapist "saved my life"

3. Growth. A negative experience leads to psychological or interpersonal growth, fulfillment, actualization, strengthening, individuation, etc. Most often, B is a personal/psychological benefit that results for the person from the occurrence of A. Examples:

death of father ---> brings family closer together

injury ---> S learns to be self-sufficient

S is lonely as a child ---> because of this S feels he/she more resilient as an adult

unhappy employment situation ---> S quits and finds independence, fulfillment

depression ---> initiated personality change

panic attack ---> self-understanding

failed love affair ---> S becomes more assertive

mother's death ---> S feels closer to her now

episode of anger and crying about father's death ---> S no longer stutters, decreased anxiety

ran away from home, felt bad ---> S gained personal strength

divorce ---> developed better relationships with children

got fired from job ---> comes to see self as a "whole person"

sexual philandering, drunkenness, fear had AIDS ---> S started taking responsibility for life

death of grandson ---> S re-prioritizes life

family stress and pressure ---> S puts life in perspective, come to value friendships more

S is threatened by angry mob ---> becomes more self-confident, resilient

husband has affair ---> S feels enhanced "strength of ego"

fight with mother-in-law ---> S experiences personal growth

illness, radiation therapy ---> S experiences better self-understanding

drugs, dereliction ---> S moves to new place, changes name, "got life together"

uncle dies ---> S experiences greater empathy for others

near-death experience ---> S sheds self-centered qualities

illness forces S to end career ---> S takes up painting and finds the "love and passion" of life

miscarriage ---> S now appreciates "the little things in life"

S feels he is arrogant and hypocrite ---> S becomes humbler, happier

4. Learning. A person gains new knowledge, wisdom, skills, etc. from a negative event. Whereas growth generally refers to psychological or interpersonal benefits, learning refers to benefits that are more instrumental and less concerned with issues of personal and interpersonal adjustment. Of course, the two types overlap somewhat. Examples:

father is dying ---> father gives sage words of advice

S is worn out at work, exhausting work load ---> S realizes life needs more balance

family poverty means S cannot go to the prom ---> learns lessons about honesty, money

severe criticism from co-workers ---> S becomes better employee

frustrations on job ---> S learns patience

tough neighborhood, fights ---> "but I learned a lot"

near-death experience ---> learned to fear death no longer

turmoil in school ---> S learns new perspectives

mother-in-law hates S ---> S learns how to be a good mother-in-law as a result

S is unhappy, quit school ---> S learns value of hard work to achieve goals

5. Improvement (and other). This is something of a catch-all category for the many examples that do not fit into the four types about but in which a bad situation containing negative affect becomes a better situation containing positive affect. Examples:

bad job ---> new, better job

S experiences a period of chaos in life ---> S experiences happiest time in life

infertility ---> a child is born (similar to recovery type)

very bad marriage ---> very good marriage

S experiences job insecurity, doubts ---> S wins award for excellence

girlfriend is depressed about her family ---> S proposes marriage, which lifts her mood

miserable about unemployment ---> stranger gives S a tip, which leads to a good job

divorce, anger ---> S becomes successful in order to prove her own worth to ex-spouse

death of brother, bad grades at school ---> "things then picked up," better grades, S is happy

hated school --> began liking it

fight and injury ---> S becomes friends with his opponent

S is a terrible student ---> summer reading program enhances confidence

very bad year at college ---> S ends up getting grades of "A"

S is terrified of public speaking ---> S improves speaking ability, experiences success

husband is cold, distant ---> S gets help, counseling, marriage improves

lonely, depressed ---> S experiences conversion to Christianity, feels ecstatic

S drifts into drugs ---> S joins track team and gains direction and purpose in life, stops drugs

unwanted pregnancy ---> S gets life focused, she becomes thankful for pregnancy

S is stuck in low-level job ---> S gets promoted and becomes very successful

The Subcategories: Agency Enhancement, Communion Enhancement, Ultimate Concern

Tedeschi and Calhoun (1995) write that three common positive results of posttraumatic growth are (1) improvements in self, (2) improvements in interpersonal relationships, and (3) enhanced spiritual or religious experiences. Employing Bakan's (1966) distinction between agency and communion as well as the language of Paul Tillich and other theologians, we have reformulated these three into the subcategories of

Enhanced Agency

Enhanced Communion

Ultimate Concerns.

For enhanced agency, score +1 if the transformation from negative to positive in the story produces or leads to an additional enhancement of the protagonist's personal power or agency, if it builds self-confidence, efficacy, or personal resolve, or if it provides the protagonist with insight into personal identity. The author must explicitly state that enhanced agency was a result of the redemptive sequence.

For enhanced communion, score +1 if the transformation from negative to positive in the story produces or leads to an additional enhancement of the protagonist's personal relationships of love, friendship, family ties, and so on. The author must explicitly state that the enhanced communion was a result of the redemption sequence.

These two subcategories -- enhanced agency and enhanced communion -- function as "bonus points" for redemption sequences. They are points that are added on to an account that already scores for redemption imagery. However, the coder should use the bonus points sparingly. The rule of thumb is that each of these two sub categories can be scored +1 only if it is expressed as a direct result of the move from negative to positive states. In other words, once an A --> B sequence has been detected (score +1 for redemption imagery), then the coder looks for additional benefits that go beyond the original redemptive move. For example, an account may score for redemptive imagery by virtue of a young man's move from drug addiction (A) to recovery (B). The "good" outcome is the recovery from drug addiction. If in addition to this good outcome, the young man also experiences enhanced friendship or love, then the account gets an extra point for the subcategory of enhanced communion. These two subcategories are value added. They enable the coder to give occasional extra points for accounts that provide multiple benefits or aspects to the good outcome (B) that follows the negative state (A). By contrast, an account in which a young woman's experience of loneliness (A) is followed by an experiences of deep-felt love (B) would not score for the extra point of communion enhancement because the actual move that makes for the redemptive imagery itself (which is, of course, scored) is itself a move from loneliness (no communion) to love (communion). There is nothing to "add" -- the redemptive imagery category capture it all. Thus, the subcategories of enhanced agency and

enhanced communion are only added to the score when the minimal content that produced the redemptive imagery to begin with leaves behind other, associated content suggestive of additional agentic or communal benefits in B.

For ultimate concern, score +1 if the transformation from negative to positive involves confrontation with or significant involvement in fundamental existential issues or ultimate concerns. The event brings the protagonist face-to-face with death, God, and or religious/spiritual dimensions of life. A point is added for this subcategory because of our belief that redemptive accounts that include such content have a more powerful and personally meaningful quality to them than do other kinds of redemptive accounts.

Total Scores

The coder simply adds up the scores from the prime test and three subcategories for each scene account. Thus scores for a single scene range hypothetically from 0 to 4. The most common score, by far, is 0. Total subject score is the sum of all scene scores.

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Appendix G

Coding System for Contamination Sequences

Rev. 3/15/98

Retrieved from <http://www.sesp.northwestern.edu/foley/instruments/contamination/> 2/23/2010

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Background

In a contamination scene, a good or positive event or state becomes bad or negative. That which was good or acceptable becomes contaminated, ruined, undermined, undone, or spoiled. Positive affect gives way to negative affect, so that the negativity overwhelms, destroys, or erases the effects of the preceding positivity. For some narrators who describe very difficult lives, scenes may begin with an acceptable or mildly positive state, but the typical pattern of spoiling or contamination with negative affect follows. One woman describes a rare moment of pleasure when her sister organizes a birthday surprise for her, but spoils the positive memory with the observation that “To me, good things just don’t happen.” Another woman summarizes her entire life story with the comment, “Good things happen, but they are always canceled out by an even worse thing happening next.” In contamination sequences, things may go from very good to bad or from barely acceptable to worse.

The concept of a contamination scene is similar to what Tomkins (1987) termed a “nuclear scene,” wherein an episode of positive affect is quickly transformed into one of strong negative affect, leaving a legacy of ambivalence that may build into a full-blown nuclear life script (see also Carlson, 1988). Tomkins argues that such scenes are most influential when they occur in childhood and are experienced as extremely intensive and confusing. May (1980) describes episodes of enhancement/deprivation in dreams and fantasies, wherein the hero first rises to great prominence (good) and then comes crashing down to earth (bad), as literally depicted in the myth of Icarus. Such a fantasy pattern is noticeable in Thematic Apperception Test (TAT) stories told by men, May suggests, while the opposite pattern of deprivation/enhancement (bad leads to

good) is more characteristic of women's fantasies. The heroic strivings of Icarus are followed by tragic consequences. But the "mistake" of flying too close to the sun offers possible positive interpretations, and might be explained as the impetuosity of youth, or even the endeavor to reach an exalted goal. This kind of optimistic spin, however, does not prevail in the autobiographical reconstruction of contamination scenes. Instead, in contamination sequences the consequences are so negative that sometimes it may have been preferable to forego the preceding positive event. The spoiling or contamination often seems to cling persistently, like rotting food that ruins all it touches, or heavy baggage that cannot be left behind and affects everything one experiences.

In some ways, a contamination scene is the opposite of a "redemption scene," in which bad turns to good (McAdams, Diamond, de St. Aubin, & Mansfield, 1997). However, the opposition is not exact. In redemption scenes, the initial bad state or event leads to a good state or event, but the good does not typically undo or erase the bad. For example, a narrator describes the death of her mother, a bad event, followed by her family becoming closer, a good event. Her mother is still dead, and death is bad, even though the family becomes emotionally closer as a result of the death. Mother's death leads to, or even causes, the closeness to occur, but the closeness does not erase or undermine her death. By contrast, in contamination scenes, the subsequent bad event often does undermine the preceding good one. The good event is ruined or spoiled. It cannot be recalled without pairing it with the bad outcome. Even its original goodness may be lost. For example, (retelling the events out of chronological sequence) a narrator recalls having been beaten by her spouse, and now states that her previously good marriage was never actually so good as she originally thought it was. The whole marriage is retroactively spoiled.

Thus, in some contamination sequences, the initial positive event or state is spoiled. Its positivity is partially or completely erased. As a result, the account of the initial state is often affectively flattened. In coding, it may be difficult to determine how positive the initial state actually was. The essential component is that it deteriorates. Things get worse. The following state or event is less desired, more negative, more painful, more bleak.

The change from good to bad states requires contiguity and chronological sequencing but may vary in other ways. The events or states described must be contiguous in occurrence, with the good preceding the bad. However, frequently the narrator describes the negative outcome or downturn first and then relates the preceding positive event or preferable state. The order of narration is not important, but in chronological time, the good must have preceded the bad.

Also, the relationship between the initial and following event or state may be one of opposition or one of association. The relationship is not necessarily causal.

Example of good and bad events or affective states as opposites:

Receives a gift --> gift is stolen

Wealth --> poverty

Leading the pack in a race --> collapses, finishes last

Pride at graduation --> shame at father's criticism of her weight

Feels appreciated by teacher --> teacher publicly scolds her

New house is a joy --> repair and bills become a nightmare

Receives help from someone --> receives criticism for needing the help

Believes marriage is good --> partner wants divorce

Examples of states or events associated by their temporal or logical connection:

Is playing happily in a park --> cannot find parents

Enjoys senior class party --> class breaks up, loses contact with friends

Gets a promotion --> new job has many hassles

Describes joy at birth of child --> states that next child died

Looks forward to class trip --> is horrified by the poverty she sees

Finally establishes good relationship with a women --> they become homeless

Common Themes

In a contamination sequence, many of the negative events, states, or affects could be categorized under general headings. The following list is not exhaustive: for example, the contamination sequence of enjoying a stolen watermelon and then suffering punishment does not fit the categories listed.

Victimization: physical or verbal abuse, theft

Betrayal: affairs, telling secrets

Loss: of significant others, job, money, property, self-respect, respect for another

Failure: in school, sports, job, courtship

Physical or psychological illness or injury

Disappointment: things do not turn out as expected, things go wrong

Disillusionment: correction of a positive misperception, e.g. role model betrays own teachings

Sex: enjoyment turns to guilt, humiliation, etc.

Some common themes overlap (e.g. victimization and betrayal), or a contamination sequence may contain a combination of themes, such as victimization, disillusionment, and loss. To form a sequence, of course, the negative theme must follow a more positive or acceptable state.

Coding

The presence of any contamination sequence in a single scene or critical event (Peak, Nadir, etc.) results in a score of +1. The absence of any contamination sequence in the scene receives the score 0. These are the only scores used.

Multiple contaminations in the same scene still receive the score of +1. Particularly for persons who do not experience much positivity, like the woman who said good things just do not happen for her, one good event may go bad in several ways. For example, one narrator's peak memory is his elation and excitement on the day of his wedding, but, he continues, the civil ceremony was a disappointment, the judge was later convicted of a crime, the video of the wedding turned out blank, and his bride became upset that he had invited old girlfriends. His positive affect is

spoiled by four different negative turns, any one of which constitutes a contamination sequence. Alternatively, several different transformations of good to bad may be crammed into a single scene.

In the case of death, a statement such as “my mother died” is not a contamination sequence. There must be some clear statement either:

- a) that the death is significant and follows a more positive state; for example, the narrator’s aunt is her role model, best friend, and very important in her life --> her aunt dies suddenly, or
- b) that the death leads to a bad outcome; for example, a mother dies and her daughter drops out of school, has a difficult time, and begins using drugs; it is strongly receding state implied that the preceding state was more positive. This would not be a contamination sequence if the narrator describes equally negative events preceding the death.

Coding Summary

1. Negative events or affects follow positive ones in chronological time.
2. The order in which events are recalled or narrated is not important.
3. The preceding positive event or affect may range from strongly positive to acceptable.
4. The account of the initial state is often affectively flattened, and the degree of positivity may be subtle.
5. It seems that good events cannot be recalled without being paired with negatives.
6. The subsequent negative event, state, or affect may be a downturn, an undermining, undoing, or spoiling of the previous event, state, or affect.
7. The preceding positivity is partially or completely erased or spoiled.
8. The relationship between positive and negative events, states, or affects may be one of opposites, or of temporal or logical association.
9. The common theses of victimization, betrayal, loss, failure, disappointment, disillusionment, or physical or psychological illness or injury may aid in identifying negative events or states.

10. A contamination sequence is not automatically signaled by mention of a death. However, a contamination does occur when the person who dies was a significant positive influence, role model, or friend, or when the death results in clearly negative outcomes and not a mere continuation of an equally negative previous state.

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Appendix H

Understanding the Likert-type scale- Pretest

1. I like to eat rotten food.

Never Sometimes Fairly Often Nearly Always

2. I like money.

Strongly Disagree Disagree Neither Agree or Disagree Agree Strongly Agree

3. Everyone should be safe.

Strongly Disagree Disagree Neither Agree or Disagree Agree Strongly Agree

4. People with disabilities should not work.

Strongly Disagree Disagree Neither Agree or Disagree Agree Strongly Agree

5. I like to go for walks

Never Sometimes Fairly Often Nearly Always

6. Children should have their own bed to sleep in.

Strongly Disagree Disagree Neither Agree or Disagree Agree Strongly Agree

Adapted from Powell, R. (2003). Psychometric properties of the Beck Depression Inventory and Zung Self-Rating Depression Scale in adults with mental retardation. *Mental Retardation* (41). 88-95.

Appendix I

Demographic Data Sheet

Number #

Age

Gender

Ethnicity (self described) White/Caucasian, African-American/Black, Hispanic, Native American, Other

Religion: name, participates in church yes/no, how often

Residential/Living Arrangement

Living at home with family member include who;

Living at home, caregiver present, no caregiver (nonfamily member)

Living with roommate caregiver present or no caregiver

Living in a home with more than three people

Other arrangements:

County of Residence:

Primary day activity and how often

Current sources of income can be combination (work income; SSDI, SSI, other)

Who did person live with during school years (family composition), including siblings/gender, current age of siblings; single or both parents

Educational History attended what schools, attended special education (type of special education), and ages attended special education), year graduated from high school; additional education

Date completed

Appendix J

Consent to Participate in a Research Study

Identity Making Process of Persons with Intellectual Disabilities

WHY ARE YOU BEING INVITED TO TAKE PART IN THIS RESEARCH?

You are being invited to take part in a research study about how people think about themselves, how they feel about themselves and their lives. You are being invited to take part in this research study because I am interested in talking with people with disabilities and letting them tell their own stories about themselves.

If you volunteer to take part in this study, you will be one of about 12 people to do so.

WHO IS DOING THE STUDY?

The person in charge of this study is Carolee Kamlager, (that's me). I am a student at the University of Kentucky College of Social Work. My advisor, who helps me and guides me in my research is Dr. Jim Clark. He is a professor of Social Work at the University of Kentucky. There may be other people on the research team assisting at different times during the study.

WHAT IS THE PURPOSE OF THIS STUDY?

By doing this study, I hope to learn about how people feel about themselves and how they define who they are. I hope to share this information with persons like yourself and also with professionals who work with persons like yourself so that they better understand and appreciate how to support persons to do the things that they want to do.

ARE THERE REASONS WHY YOU SHOULD NOT TAKE PART IN THIS STUDY?

I am talking to persons who are between the ages of 21 and 65 years old and have attended special education classes or who have been labeled by others as 'slow', 'mentally retarded' or 'having problems learning'. If you do not fit in this category you will not take part in this study.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?

I will talk to you in a place that is quiet and private. We will decide together the time to meet. This can be done at the program you attend, at your house or somewhere else that you choose. The interview will take about one hour, maybe a little longer. If we need more time, we can schedule another meeting. If you want I will get back with you after I do the interview to be sure that I have understood what you have told me. This may take another hour. We will meet at least one time for an hour, or maybe two or three times, if you want to and if I need more information.

WHAT WILL YOU BE ASKED TO DO?

I will ask you to tell me your life story like it was a movie. We will not make the movie but pretend. I will ask you about who and what would be in the movie. I will ask you the title of movie of your life story. I will also ask you to tell me about important people in your life, what your goals are in life and things that you like to do. I will also ask you to talk with me about how satisfied you are in your life.

We will talk about your life story and these other questions for one visit and maybe two if we need to.

I will tape record our talking together and write notes.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

To the best of my knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

You may find some questions that I ask you to be upsetting or stressful. If you don't want to, you do not have to answer the question. If you do answer and become upset, I will give you time to relax. We can go on if you want or we can stop. It is up to you. If this continues to be troubling to you, I can tell you about some people who may be able to help you with these feelings.

Besides this risk of becoming upset about what we talk about, you may experience a previously unknown risk or side effect.

WILL YOU BENEFIT FROM TAKING PART IN THIS STUDY?

There is no guarantee that you will get any benefit from taking part in this study. However, you may find out that talking about yourself and your life makes you feel better and understand some things about your life. Also, what I find out from you talking and listening to you and others will help others better understand people like yourself and to make them be better staff and planners for your programs. Your willingness to talk with me, may, in the future, help society as a whole better understand people with disabilities.

DO YOU HAVE TO TAKE PART IN THE STUDY?

If you decide to take part in the study, it should be because you really want to volunteer. You can say no, I don't want to do this.

IF YOU DON'T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to be in the study, there are no other choices except not to take part in the study.

WHAT WILL IT COST YOU TO PARTICIPATE?

There are no costs associated with taking part in the study.

WILL YOU RECEIVE ANY REWARDS FOR TAKING PART IN THIS STUDY?

You will receive a \$10 gift certificate for taking part in this study. You will receive this gift certificate after we have finished talking on the first visit. The gift certificate will be for a restaurant that you can use whenever you want.

WHO WILL SEE THE INFORMATION THAT YOU GIVE?

I will make every effort to keep private all research records that identify you to the extent allowed by law. I will keep everything private, including your name and any other names that you say. No one will listen to the tape recording or see my notes except myself and people who will help me in my research.

When I write about the study I will put your information with other's information and not identify you by name in written material. I may publish the results of this study; however, I will keep your name and personal information about you private.

I will make every effort to stop anyone who is not on the research team from knowing that you gave me information, or what that information is. I will keep the tapes in safe locked place and also keep my computer records in a private place when I am not using them.

If you tell me about abuse or neglect that is going on I do have to report this.

CAN YOUR TAKING PART IN THE STUDY END EARLY?

There will absolutely be no problem if you stop anytime while we are talking. You may still attend all your programs. You will not be penalized in any way. I have nothing to do with your coming to this program. I am a guest here.

WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS, CONCERNS, OR COMPLAINTS?

Before you decide if you want to take part in this study, please ask any questions that might come to mind now. If you think of something later, if you have questions, suggestions, or complaints about the study, you can contact me at 746-9503. If you have any questions about your rights as a volunteer in this research, you can contact someone at the University of Kentucky, in the office that checks on this, the Office of Research Integrity. Their number is toll free at 1-866-400-9428. I will give you a signed copy of this consent form to take with you.

Signature of person agreeing to take part in the study

Date

Printed name of person agreeing to take part in the study

Name of [authorized] person obtaining informed consent

Date

Appendix K

Brief Assessment of Capacity to Consent

	Score
1. What is the purpose of the research that I just described to you? Response: (2=to understand people with disabilities)	0 1 2
2. What makes you want to consider talking with me? Response: (2=to help others or to talk about myself)	0 1 2
3. Do you have to talk with me to continue in this program? (name program) Response (2=No)	0 1 2
4. If you participate in this project what are some of the things that will be asked to do Response: (2=at least 1 of the following: answer questions, talk about my think of my life as a movie)	0 1 2
5. Please tell me some of the risks that you may experience in you participate in this study Response: (2= Become upset when I answer questions or am thinking about my life)	0 1 2
6. Please describe some of the good things or benefits of this research Response: (2= I will feel better about myself or I will help others)	0 1 2
7. Is it possible that this research will not have any benefit to you? Response: (2=yes)	0 1 2
8. Will you be paid anything for talking with me? Response: (2=yes, a gift certificate for \$10)	0 1 2

<p>9. How long will this take?</p> <p>Response: (2=at least one hour, maybe longer)</p>	<p>0</p> <p>1</p> <p>2</p>
<p>10. Once you start talking to you have to keep talking if you don't want to?</p> <p>Response: (2=No)</p>	<p>0</p> <p>1</p> <p>2</p>

*Based on University of California, San Diego Brief Assessment of Capacity to Consent (UBACC)

Appendix L

Contact Summary Sheet

Contact Type: _____

Where: _____

Interview # _____

Interviewee Initials _____

Interview Date: _____

Today's date: _____

1. Main concept, themes heard in interview?

a) Agency _____

b) Communion _____

c) Generativity _____

d) Stagnation_____

e) Redemption_____

f) Contamination_____

2.What stood out in the interview?_____

3.Mention of disability?

4. Emotions/significant feelings_____

5. What was forgotten in the interview? _____

6. New questions generated?

7. Plan:

Appendix M.

Recruitment talk to be given to potential project participants.

Hello. Thank you for coming to this meeting to hear about my project. My name is Carolee and I have a very interesting project that I want to talk with you about. I hope that you will want to help me with it.

I know that some people will not want to be involved in this, and that's okay. No one has to help me, it is all voluntary.

Even if you start out wanting to help me, you can stop at any time.

So, let me tell you about my project.

I have worked with persons with disabilities for many years and have made many good friends doing this. Right now I am going back to school in social work at the University of Kentucky. For me to finish my classes I have to write a paper called a dissertation. This is a very large paper and I have to have my teachers approve it. But I get to write about something that is very important to me.

For this paper, I want to talk with persons like yourselves about their life stories. I want to hear what you have to say about who you are and what are some of the important people and things that have happened to you in your life.

How does this sound to you? Any questions?

We all have our own story and I think that it is very important that social workers, teachers and professionals learn about persons with disabilities by listening to your stories.

So, I am looking for volunteers to talk with me. It will take about one hour, maybe a little

longer. I can meet you wherever you want to meet. It will be private and you only have to tell me what you want to. If we need to we may meet again. After I meet with the person, I will then write up what I heard and some ideas about what I think it means. I will then come back to the person who talked to me and check it out with him or her.

When I am finished talking to everyone, I will study the stories and write the paper about what you said.

There are three big ideas that I want to think about as I listen to your stories.

One) Sometimes bad things happen in our lives. When those bad things happen we can either learn from them and make a better life. (Who has heard about when you get lemons, you make lemonade, or a silver lining in every cloud?)

But for some people they stay unhappy and seem to never have positive things happen. We call these stories, redemption or contamination. Redemption is that good comes from bad, contamination is that it stays bad.

Two) Another idea is to figure out what people think is important in their lives. Some people think it is most important to have friends and to be with others. It is most important to be loved by others and to love others. We call this communion. How many of you know about communion from church? It is the idea of sharing.

Others think it is most important to be independent, to live their own lives, to be in control to have power. We call this agency.

Most of us, like to have both, love and power. We want to feel that we are loved and to love others and also to feel that we can make our own choices, or to be in power.

Any questions?

Three) The last idea is seeing how important it is that people feel that they are contributing to their community. For some people they want to contribute, to be active in the community but can't, others won't let them, there are things in the way. Has that happened to you?

For other people they are happy doing their own thing and are not interested in contributing to the community or maybe to their family or friends. Or they may be too depressed to do anything.

Do you know someone that wants to be active or helping in the community? Do you know anyone we want to help but others won't let them? And what about the last example, do you know someone who is too depressed to do anything?

All of us, share many of the same feelings of wanting to be loved, to love someone else and to be in control of our lives. People with disabilities have not had the chance to share these stories. So that's what I want to do, to listen to these stories and to try and see what is important in someone's life.

As I said this is all confidential, I will not use your name when I talk about my work or write the paper. And you can tell me only what you want to share.

When you tell your story I will ask you to think of your life as a movie. We will not make a movie, but pretend. If you could make a movie of your life what would it look like? I will also ask you some questions about the kinds of things you like to do and how happy you are.

When I am done with the project, I will come back here and talk about what I found. I will also share my findings with Hamilton County Board of DDS and with others, like teachers and social workers. I hope that my work will make a positive difference for people who are receiving services, that staff will know more about persons with disabilities so that they can do a better job.

Any questions?

So if you are 21years or older, and want to help me out you can give me your name and phone number and then I will call you. We will set up a time to talk. If you volunteer to help me, I want to pay you with a gift certificate to a restaurant or a favorite place to shop.

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EMPLOYMENT EXPERIENCE

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