IN BETWEEN THE LINES: A PERSONAL LOOK AT LIFELONG READING

STRUGGLES

A Thesis
Presented to
The Graduate Faculty of The University of Akron

In Partial Fulfillment
of the Requirements for the Degree
Masters of Arts

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May, 2007
ACKNOWLEDGEMENTS

I would like to acknowledge the endless support and effort made by my advisor in seeing this project to completion. Thank you, Dr. Schulze, for everything. I would also like to thank my research committee for their support and encouragement throughout this process. I want to recognize my parents, family, and friends who have patiently waited a long time for me to complete this endeavor. I would also like to thank Greg, for always being in my corner and who will be the happiest to see this “thesis” completed.
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Dyslexia, a reading based disability, may affect approximately 15% of the general population (IDA, 1997). For those who enjoy reading, who have chosen careers that involve intense reading, and who experience few struggles maneuvering through a day filled with paperwork, bills, and street signs, it may be difficult to understand what it would be like to have a lifelong reading problem. Given that survival in our society is dependent on information processing, reading, and technological skills, individuals with reading problems may experience more challenges throughout the life course. The question remains: What is it like to live with a lifelong reading problem? How do individuals with reading difficulties evaluate their own life experiences?

Having worked as an intern at a local adult literacy program, clients shared with me how their reading struggles influenced their family and social life. Over time, I came to realize that adults with reading struggles have a unique and important story to share; a story that can perhaps help to illuminate the minds of those who stand looking in from the outside. The current study aims to address the following questions: (1) What factors or events lead to positive or negative life experience for individuals with diagnosed or undiagnosed lifelong reading
difficulties? (2) How pervasive is the theme of reading problems in the narratives of the participants or are there points in the lifespan where the theme of reading difficulties is more prevalent? (3) Utilizing Erikson’s (1950) lifespan model, what are the unique transitional tasks that adults with reading difficulties face? (4) What insights can be gained regarding the social, emotional, and familial aspects of lifelong reading problems to help improve services for adults with reading difficulties?

Evolution of the Study

The concept for this research project has progressed throughout my undergraduate and graduate studies. I began reviewing the available literature on learning disabilities in relation to self-esteem and social development from childhood through adolescence. The culminating result of these experiences led to a 2003 literature review entitled “The Merry-Go-Round Effect: Examining the Developmental Perspective of Social Context of Self-esteem in Adolescents with Learning Disabilities” (Witt & Brdarski, 2003). The article highlights the manner in which cognitive and affective aspects of the individual influence developing self-esteem. A conclusion of this article suggests the need for future research to examine the coping strategies of individuals with learning disabilities. After gaining a better understanding of the research on learning disabilities, I moved toward applying this knowledge as an intern during my senior year for Project Learn in Medina County.
Project Learn is an adult-based literacy organization started by a missionary, Frank Laubach, which has expanded to have centers throughout the world. The aim of the program is to help adults with few or no reading abilities gain needed literacy skills. The strength of the program comes from the volunteers who serve as tutors and service personnel for the organization. I came to Project Learn as a literacy tutor working with adolescent boys with learning disabilities. As Project Learn became more inundated with demands to have policy statements and accommodations in place for adults with learning disabilities, I moved into an internship role attending conferences and creating manuals and policy statements for the organization.

At this time I realized the challenges that adults with learning difficulties face in society. Without a formal diagnosis, adults cannot receive accommodations in the workplace. However, there are many problems with the current methods of adult assessment. For example, assessment tools vary. Confounding variables, such as the compensatory effects of remediation, pose challenges to forming an accurate picture of the adult’s level of affect and cognition (Rack, 1997). Questions have also been raised about the sensitivity of assessment tools used for this population. Rack states that with increasing age there is a greater likelihood for “secondary symptoms” to exacerbate the underlying reading difficulties (1997, p. 68). For example, older adults may engage in fewer writing or reading activities and avoid situations that could reveal areas of weakness. Anxiety over cognitive tasks may worsen performance,
especially in an assessment situation (Riddick, Sterling, Farmer, & Morgan, 1999).

In addition to problems with assessment and testing, adults both with and without formal diagnosis that I spoke with at Project Learn also express a social-emotional component to inadequacies. I became increasingly aware that a reading difficulty has the potential to manifest itself in various adult living situations and may be influenced by a host of environmental factors such as family relationships, previous school experience, and lack of supports. Individuals may be more vulnerable to fluctuating self-esteem, low motivation to achieve, and depression (Rack, 1997). In addition, some factors that play a role in social difficulties are related to cognitive difficulties such as the potential for the learning disabled adult to misinterpret cues or nonverbal components of communication as well as inappropriate laughing, gestures, and impulsivity (Vogel & Forness, 1992).

As these issues continued to surface in my work with adults at Project Learn, I realized that regardless of diagnosis, individuals with reading struggles have an important story to tell. I became curious, wanting to understand what positive or negative events might affect life experiences. I wondered if there was an underlying key in the life stories of adults with reading difficulties that might help unlock the door to greater understanding and better services for this population in the future.
Relevance to the Field of Family Development

While the current study examines the development of the individual throughout the lifespan, each person is part of a larger family network. There is a need for practitioners in the field of family development to understand the impact that lifelong reading struggles have on the individual as well as the family unit. Learning disabilities may affect fifteen percent of the population and reading disabilities such as dyslexia have been linked to genetic factors contributing to the disorder (e.g. Pennington, et al., 1999; Raskind, Hsu, Berninger, Thomson & Wijsman, 2000; Wood & Grigorenko, 2001). Practitioners in the area of family development have a greater opportunity to come in contact with individuals who have persistent reading struggles through social service agencies, literacy organizations, educational facilities and other family service providers. In addition to increased contact with adults, practitioners may also see the impact of genetics resulting in several members of one family unit having a similar disorder that may manifest differently in each family member. The current investigation provides more insight, from a subjective perspective, into the contributing role of the family to human development. A greater awareness among practitioners, educators, and family service agencies is needed to better serve this population in our society.

While decades of research have focused on providing appropriate academic interventions for individuals with learning disabilities, current research on family functioning related to reading disorders is scarce. Much more research is needed in order to provide the social and emotional supports that individual
and their families may need in coping. There may be ways for practitioners in the field of family development to help create programs to provide individuals families with support networks in coping with the cognitive, behavioral and affective aspects of reading disorders. While academic programs are important to occupational attainment and a level of personal satisfaction, social networks are also important for survival. There may be a way of helping both children and adults develop coping strategies earlier in life that may help buffer the difficulties in life transitions in the subsequent years. Without a clearer picture as to what types of issues adults with reading problems face, the field of family development is behind in meeting the needs of this diverse population. The current study examined four aspects of lifelong reading problems: 1) What factors or events lead to positive or negative life experience for individuals with diagnosed or undiagnosed lifelong reading difficulties? (2) How pervasive is the theme of reading problems in the narratives of the participants or are there points in the lifespan where the theme of reading difficulties is more prevalent? (3) Utilizing Erikson’s (1950) lifespan model, what are the unique transitional tasks that adults with reading difficulties face? (4) What insights can be gained regarding the social, emotional, and familial aspects of lifelong reading problems to help improve services for adults with reading difficulties?

Overview of Chapters

The remaining chapters focus on the theoretical foundation and methodology of the study. Specifically, Chapter II provides an overview of the literature regarding learning disabilities and reading problems. Attention is given
to Erik Erikson’s (1950) theory of ego development providing the basis for the current investigation. Chapter III offers a detailed description of the Atkinson’s Life Story Interview (1998) method including the historical background of this research tool and the rationale for using the life story approach. After clarifying the background of the research method, Chapter III covers the applied aspects of the research method by reviewing the process of sampling, interviewing, information collection and analysis. Also, Chapter III provides an assessment of the reliability and validity as well as the strengths and limitations of the study. Chapter IV includes the results and discussion of the study explaining the individuals’ coping mechanisms to lifelong reading difficulties and examining unique life transitions.
CHAPTER II
REVIEW OF THE LITERATURE

Whether or not a disorder such as dyslexia has been identified at a given point in the life cycle, anyone with a lifelong, persistent reading difficulty may experience emotional and social struggles managing their lives. Although there is a growing body of literature on the academic challenges faced by people with diagnosed learning disabilities, very little is known about how learning difficulties may affect individuals’ emotional and social development throughout the lifespan. Furthermore, adults with undiagnosed, persistent reading problems are often excluded from general quantitative studies on learning disabilities and cognitive aging. According to Patton & Polloway (1992), past research may have focused narrowly on the similarities between the difficulties faced by children and adults with learning disabilities as opposed to evaluating the unique transitions faced in adulthood. There is a general acceptance in the field that learning problems persist into adulthood; however, there is a lack of research examining the variables that contribute to adult life functioning (Patton & Polloway, 1992). Furthermore, adults with learning disorders may be excluded from cognitive aging studies, contributing to the lack of understanding regarding adult life outcomes.
As mentioned above, there has been the impression that some learning disabilities “go away” or an adult “just grows out of it,” but as Patton and Polloway (1992) point out, learning problems may manifest in other areas of life during adulthood such as social and vocational realms. Researchers such as Reiff, Gerber, & Ginsberg conducted extensive research focusing on the vocational success of adults with learning disabilities (1997). They noted that there were many similarities in adult adjustment problems between the groups defined as successful and marginally adjusted. The low marginally adjusted group was defined as adults without a high school degree and unemployed while the successful group had professional careers and advanced degrees. Both groups faced problems in areas such as “shopping, dating, work habits, and decision making…” (p.7). Interestingly, adults’ problems surfaced in a whole spectrum of life skills areas; however, studies examining these personal and interpersonal struggles has been and continues to be sparse. Throughout the articles published in the 1990s, one sees a repeated call to examine learning disabilities from a lifespan approach, yet in 2007 there are numerous gaps in our understanding of the issues adults with learning and reading struggles face as well as how to help adults through these transitions (Gerber, 1994; Patton & Polloway, 1992; Polloway, 1992; Reiff, Gerber, & Ginsberg, 1997). We have pieces of the story, yet there is something still missing. The research points to the struggles children and adults face at various points in development but what is happening as children are transitioning into adulthood? Is there a story written
between these lines, that only those who have lived through the experience can read?

Erikson’s (1950) theoretical model of identity formation provides a framework for understanding the impact of reading difficulties throughout the lifespan. Erikson elaborated on Freud’s psychoanalytic theory of psychosexual development by proposing that in addition to epigenetic changes of development within the individual, there is a complementing progression of social maturity derived from and individual’s interaction with their environment (1980). According to Erikson (1980), a person progresses from childhood to old age through a series of psychosocial stages. Each stage presents its own developmental tasks necessary for identity formation. Advancement to the next stage requires successful resolution of the previous task which yields what Erikson referred to as psychosocial strengths (1997). Unsuccessful resolution of the developmental task may cause the individual to regress to former phases of development (1997).

Erikson’s fourth stage of industry versus inferiority corresponds well to the issue of lifelong reading difficulties. According to his theory, Erikson notes that this point of identity development centers around the school-age child and learning. Naturally, this period of development is commonly associated with entering formal education and learning the needed skills of culture such as reading and writing. The child begins to associate the self with the ability to learn skills and interact with others (1980). The psychosocial strength of this period is
The question remains: are adults with lifelong reading struggles able to develop a sense of industry, and if not, then what impact does this have on life experiences? There is research to suggest that for an adult with lifelong reading difficulties, the middle and later years of life may include both positive and negative outcomes. Some individuals may find solace once outside of academic institutions and learn to channel creative energies toward career development. In a recent qualitative study on the outcomes of learning disabilities, Shessel and Reiff (1999) state that some adults find unique strategies in coping with their problems. In addition, the article notes that upon life reflection some adults express higher levels of self-esteem from having overcome numerous life
struggles. Furthermore, some individuals stated that lifelong struggles helped them to become more compassionate toward others, and several adults found occupations in service-oriented fields.

There are some consistent characteristics of learning disabled individuals who have successfully transitioned into adulthood. Werner (1993) cites four groups of protective qualities for the learning disabled adult such as the temperament of the individual, personal skills and beliefs, parenting styles within the household, network supports such as family and mentors, and windows of opportunity in the individual’s life. Greenbaum, Graham, & William (1996) suggest other contributing factors for success of learning disabled adults by stating that a college education, higher family SES, and awareness of their disability are key factors. Greenbaum et al. suggest that learning disabled adults become knowledgeable about their legal rights in employment situations.

While there is a need to examine the qualities of learning disabled adults with successful life coping skills in order to provide effective remediation, much of the available research points to a host of characteristics that can lead to negative outcomes in adulthood. Most obviously, an individual with difficulties in reading and spelling is inundated daily with text that must be deciphered. Daily activities such as reading the paper, writing a grocery list, or reading a medicine bottle may be tasks that nondyslexics take for granted. Shessel and Reiff (1999) also state that adults with learning disabilities may continue to have problems with time management, directional orientation, and word retrieval. As illustrated in the subject interviews, some adults faced employment problems as a result of social
problems with co-workers. Adults may have problems receiving promotions in the workplace without needed accommodations. Adults may be unwilling to disclose a disability out of fear that disclosure in the workplace would result in discrimination and other problems (Greenbaum, et al., 1996).

Another common theme among adults with learning disabilities has been termed by Shessel and Reiff (1999) as the “impostor phenomenon.” After a life spent trying to disguise weaknesses, adults with learning disabilities may fear having the disability exposed. Even in the face of career success, adults may fear losing the respect of others (Shessel & Reiff, 1999). The authors explain that the imposter phenomenon may also affect social and emotional functioning. In this study, adults with learning disabilities reported feeling more socially isolated, having greater anxiety and stress in coping with learning difficulties as well as experiencing severe headaches. Reading difficulties have the potential to permeate throughout many aspects of daily living and interaction. Do adults with lifelong reading struggles experience the same personal successes and struggles as adults with diagnoses or do they have unique transitional tasks? The proposed study will attempt to examine the successes and struggles of individuals in the context of living with a reading difficulty.

*Qualitative Research: The Life Story Interview*

Since this study was inductive and descriptive in nature, qualitative methods are necessary. A qualitative research design provided the opportunity to look beneath the surface at the hidden aspects of living with reading struggles while discovering the relationship between variables impacting life experience.
Since there were no a priori hypotheses, open-ended personal interviews allowed an initial glimpse of the challenges and coping mechanisms experienced by the participants across the lifecourse. As stated in Reiff, Gerber & Ginsberg (1997), the interview process gives the respondents more freedom to explore issues of personal relevance. Given that the participants in the current study have struggles in reading and writing skills, the interview method also minimized the level of stress and anxiety that may be produced by traditional quantitative methods of research, including written questionnaires. Increased anxiety over cognitive tasks may worsen performance especially in an assessment situation (Riddick, Sterling, Farmer, & Morgan, 1999). From my personal experiences as an intern for an adult literacy organization, adults with reading struggles are willing and open to discuss their life experiences. Open discourse seems to provide an outlet as well as a form of validation of their experiences.

In the series of studies that have examined the areas of success of adults with learning disabilities, qualitative methods of design have been used (Goldberg, Higgins, Raskind & Herman, 2003; Reiff, Gerber, & Ginsberg, 1997; Werner, 1993). Qualitative studies have gained more acceptance in the area of adults with learning disabilities because of the need to understand how variables interact with each other (Goldberg et al., 2003). As the current study aimed to understand the experience of lifelong reading difficulties, utilizing the life story interview method as purposed by Atkinson (1998) served as a beneficial tool for meeting these objectives.
In order to uncover the hidden aspects of reading difficulties throughout the lifespan, I searched for a method of inquiry that would provide participants the greatest flexibility in exploring their own stories. At the same time I hoped to gain the needed depth and breadth of personal history to be able to evaluate the pervasiveness of reading difficulties through the lifecourse. The Life Story Interview as outlined by Atkinson (1998) provides an interdisciplinary approach to understanding first-person narratives. According to Atkinson, a life story is defined as:

A life story is the story a person chooses to tell about the life he or she has lived, told as completely and honestly as possible, what is remembered of it, and what the teller wants others to know of it, usually as a result of a guided interview by another (p. 8).

Atkinson relates life stories as a synthesis of historical, ethnographic, and literary information. The basis of this tool comes from an ancient tradition of storytelling as a means of preserving culture (Atkinson, 1998). Through the course of academic investigation, the use of individual narratives as an academic tool has continued to increase. One can see threads of a life story approach used in psychology, sociology, anthropology, literature and history. The initial research questions set forth in chapter one, require a research method with the ability to gather information from a variety of perspectives and time periods.

The Life Story Method and Erikson’s Life Cycle

Ultimately, the current study examines the development of ego identity within a sociological context. McAdams notes that the construct of identity takes
on the form of a story (2001). He proposes that life stories provide a reflection of a person’s identity within a given social and historical context. “Life stories are psychological constructions, coauthored by the person himself or herself and the cultural context within which that person’s life is embedded and given meaning” (p.101).

According to Erikson, identity formation occurs during adolescence with the synthesis of past life experiences and prior identity labels (1980). For example, a young adult begins to bring together all past labels such as, “I am helpful, funny, trustworthy, clumsy, not athletic, not a good academic student, but I am honest.” The adolescent can fuse together a positive identity and become resilient even despite past labels that may seem negative such as being a poor academic student. However, the concern is that the adolescent may begin to see himself as a disperse entity finding himself on the fringes of society. Erikson notes that often the lack of occupational identity may contribute to ego diffusion (1980). The nature of reading difficulties may impede satisfactory occupational achievement, therefore, combining Erikson’s theory with Atkinson’s method of inquiry may yield a better understanding of factors associated with positive or negative life transitions throughout the life cycle.

McAdams (2001) asserts that life stories provide direct access into the identity of the individual. The manner in which individuals describe life events and organize relevant details provides clues to the manner in which individuals make meaning from their own experiences and see themselves in the larger cultural context (McAdams, 2001). McAdams further demonstrates the manner in which
the life-story interview method and Erikson’s theory of lifespan ego development complement each other (2001). The life story method is a beneficial tool for seeing the transitions as they occur through the lifespan.

Atkinson comments that the life story method of inquiry provides a direct look at an individual's representation of life experiences (1998). Comparable to pulling back the layers of an onion, the life story method can demonstrate how identity formation occurs or what events and interpretations may lead to potential struggles. In general life stories are personal narratives of one’s life experiences. Atkinson’s method (1998) provides flexibility in highlighting or expanding important experiences.

The goals of this study include: (a) examining what factors or events lead to positive or negative life experience for individuals with diagnosed or undiagnosed lifelong reading difficulties, (b) examining how pervasive is the theme of reading problems is in the narratives of the participants or whether there are points in the lifespan in which the theme of reading difficulties is more prevalent, and (c) examining the unique transitional tasks that adults with reading difficulties face by utilizing Erikson’s (1950) lifespan model. Given that the goals for this study are to examine the life transitions of the adult with reading difficulties and to see what impacts such difficulties may have on social, emotional and family development, the versatility of Atkinson’s model makes the life story method the principle research tool for this investigation.
CHAPTER III

METHOD OF INQUIRY: THE LIFE STORY INTERVIEW APPLIED

As noted previously, the life story method provides more than just a snapshot of factors, variables, and outcomes of an individual. The life story method provides a poignant view of life transitions and how life events are interpreted. Aside from the creative components of the method, there are scientific components that can help in generating valuable research data.

Participants

The sample size for this investigation was eight adults between the chronological ages of 21 and 65. There were five male and three female participants. This age range afforded this study the benefit of having adults who have passed through Erikson’s stage of identity formation vs. diffusion and who are transitioning through aspects of intimacy vs. isolation as well as generativity vs. stagnation. Transitions during these life phases include sustaining interpersonal relationships, seeking and maintaining occupational employment, and achieving personal and family goals.

The initial goal was to recruit twelve participants for this study, as the use of twelve adults is consistent with other such studies using the life story interview
Several factors prevented the recruitment of twelve participants. First, scheduling conflicts prevented several initial recruits from participating. Emotional concerns and fears also prevented several individuals from participating. In particular, two individuals felt that discussing painful experiences from their past would be overwhelming and counterproductive to their progress. One individual was fearful about disclosure and concern about privacy issues. Every effort was made to address participants’ concerns and questions, but some recruits had difficulty developing trust with a researcher in a brief amount of time.

Participants all experienced lifelong reading difficulties regardless of whether or not a formal diagnosis of a reading disability has been issued. Only participants that have experienced reading difficulties since childhood were recruited. Participants for this study were recruited from Project Learn in Medina, OH. Participants were pre-selected by the Project Learn executive director and program director. Aside from having a lifelong reading struggle, participants were chosen based on the following criteria: (a) meets the age parameter for the study (b) has the ability to articulate and respond to interview questions and (c) shows a willingness to participate. Informed consent was obtained in a meeting with each participant prior to or at the time of the interview process. Informed consent was provided both verbally and in writing (See Appendix A). Data collection took place at the office of Project Learn in Medina, OH, with the exception of one interview conducted in a public library conference room. A brief description of each participant will be provided in the following paragraphs.
Julia

Julia, a sixty-five year old retired home health aide, completed eight years of schooling and started ninth grade three times. She was formally diagnosed with dyslexia in her sixties. Julia is the only participant who discussed that a parent, in this case her mother, also had reading struggles. While she is unable to recall a large part of her teenage years, Julia recalled vivid stories of hiding her reading struggles from employers, spouses, and the general public. She referred to hiding her struggles as a game:

Two thirds—no, two thirds of my bosses never knew I couldn’t read. People at work didn’t know I couldn’t read. And that was one hell of a game. There’s [sic] so many people, a lot of people had no idea that their friends can’t read because we play the game so good. [sic]

At the same time Julia discussed “playing the game” or hiding her reading struggles, she also expressed a dedication to explain to others the personal experience of an individual with a reading struggle. When faced with obstacles in obtaining appropriate testing for diagnosis of her reading struggles, Julia wrote letters to various government officials and the local newspapers. She informed one unemployment official, “Because, honey, I went from unemployment all the way to Clinton’s office, and every one of them answered, and Michael DeWine sent me over here.” Her boldness in explaining her struggles to others demonstrates her resiliency. Her story reflected continually fighting through whatever circumstances in life come her way.
Jack

Jack represented the youngest of the participants interviewed. At age nineteen, Jack was the only participant currently seeking a college degree. He modified his lifelong dream of wanting to be a writer with his current enthusiasm for videogames into seeking an engineer degree where he hopes to one day write computer programs. In addition to lifelong reading struggles, Jack moved to America at age four from the Dominican Republic. In comparison to Julia, Jack also recalled hiding his abilities from others. When asked if he felt encouraged as a child to try new things, Jack replied, "I really, um, made um everybody think I was slower than I was. "One surprising response was when I asked Jack to recall any prominent memories from his early schooling years. Jack replied, "Everybody made fun of me...Blocked out every other memory, hmm."

Jack represents one of the most socially isolated participants. At an age when, according to Erikson's (1950) theory, an adult would be seeking intimacy, Jack continual echoed his preference to be a "loner." He repeated at several points in his interview that his passion for playing videogames was very important. When asked how to describe him and what he felt mattered the most to him, Jack replied, "A videogame player... playing games."

Mike

Mike also represented one of the younger participants. At age twenty-five, Mike had completed eight years of schooling. Mike and Jack also share a commonality in that both participants were put on Ritalin during their early school
age years. The following excerpt illustrates Mike’s most prominent memories of elementary school:

Mike: Sitting in the LD classes (laugh). That’s the only thing that I can really remember.
Interviewer: Um, tell me something about that? What do you remember the most about that?
Mike: Like it was, it was always just a class, 11 kids. I like never sat like in a normal classroom after the fourth grade. That’s when they found out that I couldn’t read. That I had a reading (pause) problem and basically they gave me all sorts of drugs (laugh) cuz I couldn’t, I was a like test kid for Ritalin and all the new ones that they have now…I was like one of the test kids. Cuz that was the time when I was growing up that they were giving it.

As Mike’s parents divorced during his childhood, he feels that this family circumstance was one of the greatest transitional periods in his life. In addition to dealing with his parents’ divorce, Mike recalled being arrested on his eighteenth birthday. He spent a portion of his early adulthood struggling with drug use and attempting to pull his life together. He feels that at this point in his mid-twenties, his life has finally come together. His occupation in automotive restoration has helped him fulfill a long time childhood dream of fixing cars, and Mike noted that his job is what matters the most to him at this point in his life.

Karen

Karen represents one of several middle-aged participants. She left school after the sixth grade; however, at forty-seven Karen has recently completed her GED. While her occupation is a night stocker at a local grocery store, she identifies herself as a mother of four and grandmother of five children. A factor that contributed to Karen’s early reading struggles involved her family and social status. Karen acknowledged that her older sister was more responsible for her
upbringing as a child. As the following passage notes, there were several factors contributing to her upbringing that would later contribute to her reading struggles:

Karen: Well, um my father stayed in the bars all the time and my mom was always at work. I never went to school. Always stayed out as late as I wanted to. It was like we raised ourselves, me and my sisters and brothers…
Interviewer: Anything else about that (inaudible) neighborhood that stood out to you?
Karen: It was a very poor neighborhood. That's—when I look back now to how poor that neighborhood was.

Mark

The theme of poverty and lack of emotional support during childhood also appeared in Mark's life story. When asked to describe his cultural setting, Mark replied:

Ah, (pause) I guess we were just a poor family. You know, as kids we lived in a rough neighborhood. So, at an early age, you really had to take care of yourself. Yah, anytime you went away from the house, you know, you usually you know, you were in a fight or something (laugh) like that.

In response to the question regarding his parents' emotional qualities, Mark accounted a turbulent home life:

My parents, well I could tell you a little bit about them. They were very young when they married. My dad was 17 my mom was 15. Ah, you know, they two people who probably should have never have been together. They were, ah, I think they had their own emotional problems, but you know, two people like that, you know, coming together, it was just chaos.

At age 45, Mark has witnessed many difficulties and hardships. Mark dropped out of school at age sixteen. In addition to struggling with reading and academics, Mark's mother murdered his father when Mark was seventeen years
old. As the family was segmented by child services, Mark was able to live with his older sister. Through his late teens and early twenties, Mark had a series of occupations and one marriage at age eighteen that led to divorce after a few years. Currently remarried, Mark is now a father of five children and works as a mattress builder in a local factory. Mark’s life has been filled with one challenge after another, yet his life story demonstrates the resilience of an individual to overcome his circumstances.

*Gloria*

Gloria, a forty-four year old hospital housekeeper, has completed twelve years of schooling and is currently looking into attending a local university. As a child, Gloria noted that she experienced anxiety in addition to her reading struggles:

Gloria: Well yes, when I couldn’t comprehend or understand, I got anxious... And um, yeah I got real anxious and a little hyper, like I couldn’t complete, if I couldn’t understand and complete, if I couldn’t comprehend then I was kind of upset. Interviewer: Was there somebody else to help you through it? Gloria: I would raise my hand and call the teacher to come over.

Gloria also revealed that not all of the family backgrounds included poverty or lack of supports. She expresses a supportive family structure.

Oh, I had a good strong family. Um, my neighbors they were really nice. Um, as a matter of fact, my next door neighbor, she was wonderful to us, when my mom went to work she would keep us and send us off to school...
In response to the question regarding her parents’ emotional qualities, Gloria stated that, “Both of their personalities were wonderful. They were beautiful people.”

**John**

John also provided an account of a supportive upbringing. When asked about the cultural setting in which he grew up, the fifty-two year old salt miner, noted an idyllic agrarian upbringing in a family of twelve members:

John: It was a loving household. The neighborhood was up on a little farmland. So, the closest neighbor probably four or five miles away. So, known not close neighbors. So, my close neighbors were relatives- aunts, uncles, stuff like that.

Interviewer: How would you describe your parents?

John: Loving, caring, very firm sometimes.

Interviewer: Did you get along with them?

John: Oh yeah, oh yeah.

Interviewer: Supporting family?

John: Oh yeah, my whole family 12 of us…

Interviewer: …Ok so what were your reactions to the siblings then?

John: Ah, fun, fun times.

John represents one of the participants with the least amount of schooling. He completed three years of formal schooling. Living on a farm, John started school later than most children.

Interviewer: And so you said after third grade you stopped going?

John: Uh, stopped doing, participating a lot, missing a lot of the time. You know, the, they forced, they ah, like took from third grade, and I ah went to fifth grade and I got behind (inaudible) to sixth grade…And I was going through grades but wasn’t learning nothing, so then after that, I just dropped out, because I had such a late start, when I was like in fifth grade, probably say 13 or 14 years old. So at that time it was easy to drop out then.
Stuart

Finally, Stuart, a forty-three year old laborer, has completed eleven years of schooling and is currently working on obtaining his GED. While growing up in a suburban neighborhood, Stuart recalled happy memories with his siblings, yet he admitted that his relationship with his father was always somewhat strained.

Stuart: Um, my dad, he’s rough. He worked. Worked hard, always worked hard. Uh, mom was always the housewife, stay at home mom. She had a job here and there; always stayed at home basically, did all the housework, chores, you know. We helped out, kids helped out.

Um –

Interviewer: Did you get along with your parents?
Stuart: My mom. Not my dad.

Interviewer: Not with your dad? Um, how about emotionally, how would you describe your parents emotionally? Their emotional qualities.
Stuart: (mumbles) um, let’s see. Well my dad’s hard tempered, you know. He was–He worked all his life. He worked hard all his life, if you got out of line, it was—you had to watch out for dad, not mom. Mom would always protect her kids, you know, “don’t touch them kids.” Unless we made her real mad, then she would she’d jump in there but-mom [sic] more nice, but dad (chuckles)

One of the prominent themes in Stuart’s life story involved the dissolution of the salt mining company he was employed with during the mid 80s through the mid 90s. This occupational challenge represented a large transition for Stuart, a transition that he is still learning to cope with:

Interviewer: How about as an adult, do you have any struggles as an adult?
Stuart: I still can’t, for reading a book or something, I don’t like that. And struggling; let’s see, well, at one point in my life I was doing real well, good work, good job, had a house, had a family. Lost that job. Company broke up the Union. It was about 200 people lost their jobs. I went downhill and struggling just to make it by day by
day. You know, go from twenty dollars an hour to eight bucks an hour (chuckles) it’s a struggle, you know.

When asked about how he made the transition from high school into the workforce Stuart replied:

Stuart: Just like, boom, an overnight thing, I don’t know. Just did it. (chuckles) I just, I said, great, I’m getting married, I got a good job, I don’t know, it was just like an overnight thing, I just went on with my life all of a sudden, just took off and I loved it.

Interviewer: Um, so then what would be the next transition after that?
Stuart: When um, in ’96 was when I lost that and everything just started falling apart.

Interviewer: How’d you cope with that? Now, now that’s another big change.
Stuart: Yeah, I started drinking heavy, [sic] and as I was drinking heavy um, god, started seeing things fall apart. Wife had to start working, trying to get the bills together, just to try to make ends meet every month –Killing us. After a while, we had to sell the house and move. It just kept going downhill. I don’t like all-

Interviewer: How did you cope with all that?
Stuart: Still coping with it. It’s killing me. It’s hard (inaudible).

Stuart’s current life journey involves attempting to regain the aspects of his life he lost when he lost his job. He stated that he still longs for his previous life circumstances and continues to struggle through each day.

Methods

I conducted a meeting with several prospective participants prior to the interview process to obtain consent and familiarize the participants with the interviewing process. Participants were allowed the choice of having their reading tutor present during the initial meeting for reassurance and assistance with the reading materials. At the initial meeting six participants and five tutors were present. As two initial participants withdrew from the study, other individuals were
contacted. Subsequent meetings were scheduled at the convenience of the
participants. Two participants met with me with their tutors present, and two
chose to meet with me without their tutors present. The initial meetings lasted
twenty-five to thirty minutes. Participants had the ability to ask question regarding
the study, and all were encouraged to review the materials for several days
before conducting the interview. Only two participants signed the consent forms
after the first meeting while the other participants brought the signed consent
forms at the time of the interview. Participants were encouraged to bring
photographs if they desired to help aid in memory of life events; however, no one
brought photographs. Participants received a copy of A Life Story Questionnaire
prior to the interview (See Appendix B). The purpose of providing the
questionnaire in advance was to help reduce anxiety over the interview process
and to provide the participants the opportunity to familiarize themselves with the
questions with their reading tutor prior to the formal interview.

The purpose of using Atkinson's life story method was to uncover the
hidden aspects and pervasiveness of reading difficulties throughout the lifespan.
According to Atkinson (1998), there are several benefits of using the life story
method in generating qualitative data:

The role of a life story is primarily to pull together the central
elements, events, and beliefs in a person's life, integrate them into
a whole, make sense of them, learn from them, teach the
younger generations, and remind the rest of one's community what
is most important in life... The life story interview provides an
approach and method that can make recording and studying
personal narratives a uniform research endeavor. (p. 19)
The results generated from using a life story method are twofold. Each individual story provides a unique account of living with a lifelong reading difficulty. Specifically, examining the coping methods utilized by each of the participants taking into account external life circumstances provides new insights about the life experiences of adults with reading struggles and also provides further support to the existing body of research on adults with learning disabilities. The life stories collectively provide a representation of reading struggles across generations. Atkinson’s (1998) life story interview allowed researchers the ability to adapt questions to interviews by omitting questions or asking additional questions as needed during the interview process. In the present study, approximately twenty-two main questions were asked covering seven broad life themes. The interview included both open-ended descriptive and contrasting questions. As discussed by Atkinson (1998), descriptive questions such as “How would you describe your parents?” provide participants the greatest amount of freedom in response. Contrasting questions, such as “What has been the most important lesson in life?” provoke meaningful responses about life transitions and the participants’ perception of their own psychosocial crisis.

Each interview was audio-taped and transcribed, and information obtained in the interviews was kept confidential. Individuals’ identities will not be identified in any presentation or written document of the findings. Participants were assigned subject numbers; all other identifying information has been removed from the data and placed in files that only I have access to.
Pseudonyms will be used in conjunction with direct quotes if necessary.

Information is stored at my home and saved on computer files and audiotapes. Printed transcripts and consent forms are kept in a filing cabinet, and all original data will be kept for five years following the date of project completion.

Analysis

Interpreting data obtained from the interviews was a two-fold process. The validity of the story was of primary concern. Each story represented a case of life struggles, triumphs and meaning. By working closely with each narrator, validity and internal consistency of the life story could be maintained. Transcriptions were analyzed individually for the unique personal contribution each life story possesses. Life stories were compared to one another in an effort to create a collective story.

Analysis of data included inductive methods similar to grounded theory (Strauss, 1990). During the process of examining the interviews, the use of the constant comparison method also helped derive predominant themes from the data and show how these themes relate to the transitional tasks faced by adults with lifelong reading difficulties. Initial hypotheses served as a point of comparison for all subsequent data. The goal of this process was to develop a comprehensive and refined conceptualization of the participants’ life stories.

Coding of Data

During the process of open coding, careful examination of the data helped to form initial hypotheses of the most prominent themes in the data and how these themes relate to the larger body of research on adults with reading
struggles. Coding categories were generated based on the most prominent themes found in the data. Initial hypotheses were used as a point of comparison of all other data, and through the methods of axial coding, or further refinement, additional subcategories were created to provide a comprehensive analysis of the data. The process of revising continued throughout the coding of the data by the use of NVivo software (1999) program. NVivo allows for revision, adjusting, and combining coding categories during the actual process of coding.

In parallel with Erikson’s view of the self in society, the first coding category highlights types of Challenges and Opportunities afforded the participants. Through the Challenges and Opportunities, the category of Self-Appraisals reveals aspect of the individual, the Eriksonian, ego. Lastly, the manner in which the individual works through the challenges and opportunities forms the categories of Coping and Insulating the Self. The following paragraphs will detail the four primary categories derived from the data and provide examples of the subcategories.

*Challenges and Opportunities Coding*

The participants’ responses were coded into one of six subcategories of the Life Challenges and Opportunities associated with having a lifelong reading struggle. Responses that incorporated the subject of schooling issues, diagnosis of a reading disability or referred to the process of learning to read were coded as a challenge or opportunity in the (a) Academic realm.
Julia: At school, I had teachers that give [sic] me a hard time. In fact they skipped me from uh, fourth, let’s see I went from fourth to sixth and that’s where you get fouled up. You ever miss one grade in between, you’re in trouble. So, I had teachers that loved to give me a hard time and I’d go home crying, and my mother had to go see them but I only had one teacher that really cheered. Her brother was the principal. That was my fourth grade teacher. No, third – and she tried to help me. Back then, they had no idea about the idea about the learning problem. So, you still (inaudible) the dummy of the class. Anybody that had problems with anything, the teachers didn’t want to be bothered with you.

Mike: I used to write in Young Authors and Young Illustrators and I used to win. Figure that one out. You’ll never figure it out, but I used to, I mean up until like fifth or sixth grade. I used to, like I wrote like three books, and they’d actually win. I don’t know how it happened, but…

(b) Social Support – when participants referred to a person or network that possessed the potential to be a support or offer a life challenge or opportunity.

Mark: There was a lot of fighting in the household. You know, my earliest memory is, you know, waking up in the middle of the night and my mom and dad just, you know, I mean physical fighting and stuff and things breaking and ah, stuff like that.

Gloria: Oh I had a good strong family. Um, my neighbors they were really nice. Um, as a matter of fact, my next door neighbor, she was wonderful to us, when my mom went to work she would keep us and send us off to school.

(c) Employment – participants’ accounts of occupational challenges or opportunities.

Mark: Ah, you know, I’m thankful I have a job, I mean it’s a good paying job, you know. For someone with my limited abilities, you know, I could never make any kind of money any place else, I don’t believe, but you know, with my kids, my children are grown. I’m kinda looking, I can retire at 55 from there, and I’m kinda looking forward to that. Because what I do, building, is just labor intensive, and I’m forty-five years old. It’s really hard on my body. You know, it’s not like it was when I was twenty-three when I started.
(d) Generativity – in accordance with Erikson’s psychosocial stages, responses were coded Generativity which referred to a selfless giving or helping others and emotionally investing in the future. Investments in the future may relate to giving back to one’s family, occupation or society.

Karen: I have fun with my grandkids (laughs). I do. Like right now, little Mitchell is having a rough time reading, so ah, I got the Hooked on Phonics here for myself, so I actually gave it to my daughter to help him. You know, and then, Maria, she’s having a hard time right now in math, so I went out and got some math books and cards and so when we sit down, we had do that, and then they’ll come to me and give me tests on mine.

(e) Society – responses coded as a challenge or opportunity from society referenced social pressures, expectations from others, or cultural stereotypes.

Mark: You know, the types of people I can interact with, probably aren’t the kinds of people I should be interacting with (laughs). You know, in a lot, you know, the brighter people and that, I just don’t feel like I have a lot in common with, you know, I mean, when you’re not a reader, there’s a lot of things you don’t know. I mean, you’re not as sm-you feel as if your not as maybe good as somebody else, as smart as they are, you know just–

(f) Life Circumstances – coding for life circumstances included themes relating to life challenges or opportunities not referred to in other categories such as aging, relocation, sickness or pregnancy. Life circumstances may also include areas of familial poverty, abuse or divorce.

Mark: It was a struggle. You know, for my family. You know, my parents they could, you know they—they weren’t high school graduates or anything. We were on, you know, but they could read and write. But half the time we were on welfare. You know, we just kinda like lived the slums of town, really. I didn’t really know anybody poorer than we were. You know, I’m sure there were. I’m sure there were, but ah, day to day existence, ah, you know, ah, it was a struggle.
Self-Appraisals Coding

The category of self-appraisal statements was divided into two subcategories: (a) Self Appraisals/Acceptance – refer to statements of self assessment such as “I am content.” For example, Mark refers to a self-appraisal of the importance of trusting others in his life. "I've never been really able to trust anyone, you know. Trust has been a big thing with me.” Self-Appraisals/Acceptance coding may also refer to global assessments which may include participants’ recognition of reading struggles or resolution of transitional tasks. Such statements could either reflect positive or negative personal judgments.

Mark: …I mean, I’m light years ahead of where my folks were, but you know, you make a couple bad decisions and you know, you make mistakes along the way. Ah, you know, I carry a lot of baggage with me,…I feel my wife deserves a better person than I am, you know, cuz so much is–I’ve just been traumatized all through life, you know, in my younger years. You know, I’m just ah, I just see myself sometimes as a screwed up individual, you know.

(b) Resiliency coding refers to the participants' stories of personal triumph over difficult circumstances. References to overcoming obstacles over a span of time or being able to reflect on challenges and opportunities without regret were coded as resilient statements.

Interviewer: What do you think you’ve learned from that rough road?
Mike: How not to do it again (laughs). I mean, I learned a lot from being in that like whole situation, the trouble, the law, drugs and people. You learn a lot, cuz, you know, the other side of things is not cookies and cream. You know, the crap part of it. When I look at something, I can see both sides of the fence. Cuz where I’m at now, nobody thinks that I came up like– cuz I didn’t want to show signs of being, you know, I wasn’t a huge drug (inaudible)– I wasn’t a huge crackhead in a ditch, don’t worry, but I
was around it. I could see everything. I did the whole stealing cars, well its just good cuz I know both sides of things, so it’s like good to know–the streets smarts thing.

*Coping Coding*

The data were also coded by looking at the aspects of individual coping mechanisms. Five aspects of coding were created demonstrating the individual’s active seeking or utilizing internal as well as external resources. The coping categories were: “Support Networks,” “Fighting Through,” and “Spirituality.”

To differentiate from the previous subcategory of social support in the challenges and opportunities category, coping for “Support Networks” referred to participants’ responses of utilizing resources from individuals or networks. Coding for Support Networks includes, within the narrative, an attempt by the participant to draw on available resources.

Mike: I’ve got a couple of people. My friend Ronnie. He’s sixty something. And I talk to him. He’s known me since I was a hoodlum, I mean, he’s known me since I was like 8. He lives down the street from me and he’s watched me go through my ways of life back and forth up and down. And he supports me and talks to me and tells me what I was doing wrong and what I was doing right. He’s always been there for me.

Interviewer: No. okay. Um, was there anything about school you could think about early on that was maybe one of your best memories? Karen: There was this nun. She came over to the neighborhood and she got me to go to school with her. It was seventh grade I guess. And-she was really terrific, but I just didn’t get it. (laughs) I don’t know. I just couldn’t figure it out. Then I just got involved with the wrong people. Interviewer: So, you would consider meeting this, this nun as the happiest memory of school times? Karen: Yes, yes, because she actually took me to the side and, and tested me and gave me books and stuff like that. She tried.
The “Fighting Through” refers to participants’ responses to follow-up questions specifically relating to coping mechanisms. For example, when asked about strategies for coping with challenges or life opportunities, responses that included phrases such as “I just did it” or “I just kept going” were coded “Fighting Through.” Participants’ reflections of managing challenges or opportunities through the use of knowledge or social skills were also coded as “Fighting Through.” Employing cognitive or social skills to meet challenges and opportunities is a dynamic process of using individual strength to meet life circumstances. As the following example suggests, using active listening, memorization strategies, or interpersonal skills requires self-awareness and the ability to understand how to apply skills in a given situation.

Interviewer: Do you feel that you have inner strength?
Stuart: Yeah.
Interviewer: And where do you get that inner strength?
Stuart: I don’t know, just from inside I guess. I just keep going.
Interviewer: Well, in what ways do you experience yourself as strong? How would you describe that?
Stuart: Um, how do I feel I’m strong?
Interviewer: Yah. How do you feel strong?
Stuart: Cuz I keep going every day, I keep pushing myself. I could just go somewhere and jump off a bridge and end it all, but that’s too easy.

Interviewer: Tell me a little bit more about how you coped. What did you do to, um, get by the fact that reading was a struggle for you?
John: Uh, I made sure that I did things extra hard. And I made sure I done’m right. And I would listen. I had a very good way of listening, you know what I mean. I listen to all kinds of different things. Even, I was able to use that to do my daily activities and stuff like that. So I never was embarrassed about my reason for not knowing how to read. If I didn’t understand somethin’, somebody gave me something, I’d say, “Hey, I don’t understand this. Explain this or read it to me.”
Coping through the use of spirituality comprised the final subcategory. Spiritual coding refers to passages that reference a higher power, religion, or metaphysical elements as a resource for moving through life’s challenges and opportunities. In conjunction with spirituality, several interview questions from Atkinson’s (1998) life story interview revolved around the theme of life hopes and dreams. The coding category of spirituality also includes response that referenced hopes, dreams, or visions as a means of coping with difficulties or opportunities as these areas represent metaphysical qualities. Participants’ discussed their hopes and dreams as a means of rising above life circumstances with expectancy towards the future.

Interviewer: Yeah. Um, what has been the most important lesson that you learned from life but not something you learned in a classroom, just what you’ve learned about life in general, what would you say “this is what I learned from life?”
John: How to pray…That’s one thing my mom and dad did. They taught [sic] that prayer had a lot to do with things. And it kept me out of trouble, I’ve never been to jail, I’ve never had uh, septen (substance) abuse and stuff like that. Uh, I raised a good [sic] kids, that don’t have those same problems. Good morals. I was taught morals that (inaudible) need in life, but I have what it’s a-suppose [sic] to be to be human in life.

Interviewer: That’s right, we did talk about that in the beginning. Ok, what gives you hope? Is there anything that gives you hope? You said you’re content, you feel content so what gives you hope?
Julia: The good Lord--if I didn’t have Him, I still wouldn’t be here, an’ He’s got plans for me. Still, don’t know what it is, but there’s something! Cuz, I’ve had too many times, I should have been gone. In fact, I know three I should have been gone because uh Dr. Smith, the– that put the stint in me, didn’t think I’d come off the table, that’s how low my blood pressure was. So– there’s something. That’s the only thing that keeps you going. The good Lord, that’s all I can say. He’s still taking care of me.

Interviewer: Did you have any dreams or ambitions as a child or as teenager?
Mark: I guess, I ah, wanted to join the service and train dogs, you know, that was my big dream as a kid. You know, and ah, at that time I really, you know, I didn’t really think about reading and writing.

Interviewer: Why did you pick that as a dream?...
Mark: Well cause, you know, everything goes back to food with me. Because when I was little we just were hungry all the time. And ah, they told me you could go in there and eat all you want (laughs). I mean, you know, I thought that sounds really good, and you can travel and see the world and ah, you know, I loved dogs, and ah, I thought that’d [sic] be great travel, see the world, have all the food you want, you know.

_Insulating the Self Coding_

Initially a subcategory of coping, the final major coding category of Insulating the Self emerged through the process of constant comparison and axial coding. Utilized as a coping mechanism, participants reflected strategies of protecting the inner self from both life challenges and opportunities through the use of Isolation, Avoidance, Escapism, Abandonment of Dreams, or Repression.

(a) Isolation – includes withdrawing from social supports and networks or introversion. When asked how he broke free from the influence of his peer groups, Mike replied, “I just stopped talking to them…yah, just moved out and stopped talking to them.” (b) Avoidance coding refers to escaping situations as in the example of Karen. When asked what she remembered most about elementary school, Karen relied, “I remember cuttin’ a lot. Second grade I was always sick. Didn’t want to go to school, so, I stayed home.” (c) Escapism refers to the use of various substances and activities to substitute for actively using skills or social supports in coping with challenges and opportunities. When asking Jack to describe himself at this point in his life he replied, “Um. I’m mostly a gamer. Like, there’s only maybe a couple of friends that know who I really
am...So, my life is to play videogames.” When further pressed to explain what matters the most to him in his life, Jack replied, “Playing games (inaudible).”

(d) Abandonment of Dreams coding refers to statements including disposal of previous life dreams or changing dreams based on life challenges or opportunities. Responses in this category demonstrate the individual letting go of ideals or goals that at one point in the life cycle were important.

Interviewer: Did you dreams maybe change when you were a teenager? Did you have any other dreams, any other dreams or ambitions as you got older (inaudible)?
Gloria: Yeah, then I decided I wanted to go into child care.
Interviewer: Ok. Why did your dreams change? Why was that?
Gloria: Because I didn’t have enough of schooling and um, then I got where I didn’t go to college, um, you need some college for it. Then I got depressed and down and out, and then I got to thinking about, you know, as I was growing up from grammar school to high school, that I didn’t have enough education, that um, they um–I felt that they just passed me on through life. My reading and writing wasn’t [sic] good, and [pause] then I just kind of lost interest in my dreams.

(e) Repression category refers to the inability to recall life events as well as holding back emotions or suppressing inner abilities.

Interviewer: …did you have any major um, any major turning points, any major transitions in your life?
Julia: I don’t remember too much about [clears throat] my teenage years. That’s something I’ve blocked out. I said, well if the Good Lord ever wants me to know let me know, but otherwise it’s something I don’t need to know. I wished I did but, when I was seventeen it started working, and ah, I couldn’t get no answers, so I finally wised up and decided to let it go. It was gonna drive me crazy. Because when you can’t get an answer, you can’t get an answer.

Once the coding categories were established, overlapping themes and plot lines across participants’ stories were examined, as addressed by Atkinson (1998) and explained through the use of existing theories of lifespan...
development and research regarding reading difficulties. Specifically, Erikson’s (1950) lifespan model provided the theoretical framework for the collective story. The collective story discusses the common psychosocial crises and transitions faced by the participants. Individual as well as collective compensatory strategies in transitioning through Erikson’s eight stages of man were examined. The collective story was analyzed in relation to existing research on reading difficulties.

Collectively, the data helped to answer the questions posed in Chapter One: (1) What factors or events lead to positive or negative life experience for individuals with diagnosed or undiagnosed lifelong reading difficulties? (2) How pervasive is the theme of reading problems in the narratives of the participants or are there points in the lifespan where the theme of reading difficulties is more prevalent? (3) Utilizing Erikson’s (1950) lifespan model, what are the unique transitional tasks that adults with reading difficulties face? (4) What insights can be gained regarding the social, emotional, and familial aspects of lifelong reading problems to help improve services for adults with reading difficulties?

Limitations of the Study

While the current study provides a unique experience for adults with reading difficulties to voice their triumphs and struggles, there were several limitations of the study. Given the small sample size of eight participants, results cannot be generalized beyond the sample. Furthermore, most of the participants were recruited through Project Learn of Medina, Ohio. Consequently,
randomization of the sample was minimal. Gender and age were randomized; however, the sample mostly consisted of middle class Caucasian individuals. I met one of the participants while working as an intern at Project Learn several years prior to the study. However, I was not aware of the participant’s life story prior to the study.

Validity and reliability as defined in traditional quantitative research was not applicable to the current study. As noted by Atkinson (1998), analysis of the personal life story is subjective. Life stories were examined by their level of persuasion or the degree to which the story “seems reasonable and convincing to others” (p. 61). Adults with reading struggles are very often willing to discuss their life experiences. Open discourse seems to provide an outlet as well as a form of validation of their experiences. Consistency and trust between interviewer and participant was of more value to generating new theories or hypotheses.

Furthermore, a major goal of the current study was to use inductive and grounded theory methods rather than deductive methods to help generate theory about the lives of adults with lifelong reading difficulties. Erikson himself employed the use of psychobiographies to help generate his theory of the eight stages of man (1950). While generalizability was not a goal of the current study, the qualitative interviews conducted resulted in rich data that will be more meaningful theoretically than a large-scale quantitative investigation.
CHAPTER IV
RESULTS AND DISCUSSION

The chapter discusses from an Eriksonian viewpoint the manner in which an adult with life long reading struggles copes with the challenges and opportunities presented throughout the life course. Furthermore, the following sections addresses the original research questions (1) What factors or events lead to positive or negative life experience for individuals with diagnosed or undiagnosed lifelong reading difficulties? (2) How pervasive is the theme of reading problems in the narratives of the participants or are there points in the lifespan where the theme of reading difficulties is more prevalent? (3) Utilizing Erikson’s (1950) lifespan model, what are the unique transitional tasks that adults with reading difficulties face? and (4) What insights can be gained regarding the social, emotional, and familial aspects of lifelong reading problems to help improve services for adults with reading difficulties?

When examining the life stories together, there are numerous similarities. Looking between the lines of the stories, one becomes more aware of how lifelong reading struggles affect individuals’ ability to transition through the lifespan. The participants’ stories reveal that living with a lifelong reading struggle can have both positive and negative impacts. In accordance with Erikson’s
viewpoint, the individual, or the self, faces a series of life challenges and opportunities. Erikson’s theory hinges on the concept of the epigenetic principle, which states that there is an internal readiness for individual growth both from a physical and a psychological perspective, and at the appropriate times this growth will take place (1980). Erikson also notes that changes or personality growth come from the proper balance between maturity and opportunity (1980).

Personality can be said to develop according to the steps predetermined in the human organism’s readiness to be driven toward, to be aware of, and to interact with, a widening social radius, beginning with the dim image of a mother and ending with mankind, or at any rate that segment of mankind which “counts” in the particular individual’s life. (pg. 54)

The excerpt above demonstrates the three major themes highlighted throughout the participants’ life stories. Erikson notes that the individual needs to be intrinsically motivated to transition through various life stages and possess the necessary skills and personal awareness to cope with changes. In addition, growth comes through the interface between the self and society. Furthermore, our primary caretakers serve as the initial social base that propels the interpersonal journey.

*Impact of Life Challenges and Opportunities*

Most participants noted that their reading struggles presented either a challenge or an opportunity in various aspects of their lives. One of the most prominent categories in which the reading struggles presented a challenge was the area of academics. All of the participants, irregardless of age, reflected on various struggles from coping with classmates and teachers to understanding
classroom assignments. As Stuart noted, maintaining focus or commitment in academic learning posed a challenge to several of the participants:

I don’t know, I just –something it wasn’t interesting, I don’t know. I’d start reading a story of some sort, read a book, never finish it. I’d just lose interest in it. I couldn’t fall into a story or something.

Karen further expressed a life long struggle with “just not getting it.” By seventh grade, she was ready to drop out of school, until a nun came to her neighborhood and brought her books.

Interviewer: …Was there anything about school you could think about early on that was maybe one of your best memories?
Karen: There was this nun. She came over to the neighborhood and she got me to go to school with her. It was seventh grade, I guess. And- she was really terrific, but I just didn’t get it. (laughs) I don’t know. I just couldn’t figure it out. Then I just got involved with the wrong people.

Julia, at sixty-five, provides a retrospective glimpse at an individual with reading struggles in an academic setting.

Uh-I felt like I was a dummy so I didn’t try nothing. If you’ve been told that long enough, teachers more or less make you feel that way, you don’t even try. You give up…And when I was doing homework I had a girl who was ‘bout three years younger trying to help me. Didn’t work, and, and a neighbor one time, I got her, she could not believe I didn’t know how to read because I pronounced the English, I learned, I kept with the English where I didn’t sound so stupid. I memorized…
The one (inaudible) teacher that, she tried to help me when nobody else would. She knew something was wrong, but like I said back then nobody knew. She was the only one that figured out that I was having such a problem. [clears throat] And I was the oldest in most of the class ‘cause they kept holding me back, which didn’t do a bit of good.

Further recollections of elementary school revealed a wide range of experiences.

Interviewer: What do you remember most about elementary school?
Mark: Ah, just ah, I think ah, what do I remember the most about school? Not liking it I guess. I never liked school from kindergarten on. When they took me to test me for kindergarten I didn’t like it.

Gloria: Well I enjoyed elementary school. It wasn’t too hard, it was real easy, but um, with me, um, like I said, I would get anxious and upset if I couldn’t complete the lesson, the math, the reading. If I couldn’t understand I would get kind of upset but then I would raise my hand and ask the teacher to help me and she would kind of calm me down, tell me it’d be alright and we’d go on from there.

Mike and Jack represent the youngest two participants in the study. One might expect that, given the current legislation and tutorial programs in place in many schools, these two should have had the most positive academic experiences. Their responses, however, echo unique struggles:

Interviewer: What do you remember most about elementary school?
Mike: Sitting in the LD classes (laugh). That’s the only thing that I can really remember.
Interviewer: Um, tell me something about that? What do you remember the most about that?
Mike: Like it was, it was always just a class 11 kids. I like never sat like in a normal classroom after the fourth grade. That’s when they found out that I couldn’t read. That I had a reading (pause) problem and basically they gave me all sorts of drugs (laugh) cuz I couldn’t, I was a like test kid for Ritalin and all the new ones that they have now…I was like one of the test kids. Cuz that was the time when I was growing up that they were giving it.
Interviewer: Um, do you have a best memory of school?
Pause.
Mike: Um, I don’t know. I really don’t remember much about it.

Interviewer: Um, do you have any memories about just being in school whether your best memory, your worst memory?
Jack: Everybody made fun of me…Blocked out every other memory, hmm.
Interviewer: That, was that, what stayed in your mind the most.
Jack: Yes.
Interviewer: During those years, did you have any favorite teachers?
Jack: Not really.
Interviewer: …How about any accomplishments, did you have any accomplishments that you are proud of?
Jack: Nope.

As many of the participants left the academic realm prior to graduation, they sought to develop a sense of industry in their occupational pursuits. The category of employment presented both challenges and opportunities through the life course. For many participants, finding success in the employment domain fostered feelings of achievement and success. In response to the question about the easiest part of his job, Mike responded:

The whole thing, in general. I mean, there are some things that are harder than others, but I can go to work and do—I know what I have to do. Even though I don’t know what I have to do. I still let my boss- tell me what he—still teaches me cuz I’m new to the old car thing. So, he still teaches me, and I still let him tell me cuz I want it done the way he wants it done. So, but it’s just like natural. You only tell me once and I do it. It’s really the only thing I know how to do (laughs).

Several of the participants still faced new challenges in the work force. Having a lifelong reading struggle presented challenges in completing necessary paperwork, job application forms, and gaining promotions as some participants avoided taking tests needed for career advancement. Interestingly enough, for many of the participants, this transition from school to work demonstrated a delayed progression through Erikson’s eight stages of man (1980). Without having completely acquired the social tools to compete in an information society, many of the participants would use the employment realm to develop life skills and foster a sense of competency through more physical forms of occupation. The life stories reveal that all of the participants struggled with Erikson’s fourth
stage of industry vs. inferiority, combining this transition with Erikson’s stage of identity vs. identity diffusion (1980). While all adults need to learn to transition from being a student in the academic realm into being a worker in the employment realm, adults with lifelong reading struggles may experience the transition in advance of the psychological readiness to cope with the challenges.

Additional life challenges and opportunities for individuals with reading struggles came in the form of people. All but one participant noted having a positive social support person in his or her life. For many of the participants the primary support person was a sibling, family member, or spouse. Secondary support people included friends, teachers, neighbors or coworkers. The support network provided opportunities in the life of the participants in many ways such as supporting goals, providing employment opportunities, or providing residence during times of occupational transition. Having family, friends and coworkers also provided the opportunity for several of the participants to “give back” to others. According to Erikson (1980), participating in the growth and nurturance of future generations is the act of generativity. One of the main ways that the middle-aged participants felt they were helping future generations was by advocating the importance of education to their children and grandchildren.

However, social supports also posed challenges. For example, lack of family support or understanding about the individuals’ reading struggles created emotional challenges. Julia’s story represents a generational view of learning struggles, as she noted that her mom was also dyslexic.
My mom, we know she was the one that has dyslexia. My dad, he was, he was all right. But, uh, my mother was another story. She just couldn’t see it, and uh, [clears throat] that’s what hurts the most is, I would try, but I got accused of everything. So, I really quit trying.

Furthermore, individuals such as employers, coworkers, and other members of society posed challenges through lack of understanding. Participants discussed ways in which they would have to explain their reading struggles to coworkers or spouses. Since many of the participants had learned to cope with their struggles, they would be met with disbelief or lack of understanding. These challenges clearly affected interpersonal relationships.

**Family Support**

In looking back to the original research questions of this study, one can see that the category of challenges and opportunities helps to put together several key factors which are important in understanding the lives of adults with reading struggles. First, the initial family structure serves as the base from which the individual learns how to interact with society. For several of the participants, family issues such as abuse, violence, divorce, and poverty may have impacted reading development in indirect ways. Based on the experiences shared by the participants, family issues took precedence over learning issues. As Mark noted from his childhood experience, he found paying attention in class difficult when he was hungry all the time. The family could also serve as a buffer from life challenges. All but one of the participants noted that they had at least one sibling who helped provide support. Siblings were often mentioned as the first support network person. Supportive family structures gave individuals more confidence to
try new things during their childhood years, thereby opening the door to a variety of life experiences.

An important point to note is that having an unsupportive family did not translate into negative life outcomes for adults. Several participants overcame difficult life challenges; however, these same adults noted that having a lack of support early on in life made the journey more complicated. As discussed by Werner (1993), adults having lifelong learning disabilities are able to overcome even the gravest of early life experiences. Werner notes that several protective qualities for the learning disabled adult are temperament of the individual, personal skills and beliefs, parenting styles within the household, network supports such as family and mentors, and windows of opportunity in the individual's life (1993). The life stories of the participants in this study echo several of the same factors noted in Werner’s longitudinal study of learning disabled adults. Therefore, when looking at what factors or events contribute to positive or negative life experiences for adults with reading struggles, the family or early support network appears to be an important contributor at helping the individual build the internal readiness to face life transitions.

Unique Life Transitions

A second factor revealed through the life stories involved the unique life transitions faced by adults with lifelong reading struggles. While the transitions faced by adults with lifelong reading struggles are similar to the transitions outlined by Erikson, it is interesting to examine the manner in which adults with lifelong reading struggles cope with these transitions. Constructive coping
strategies identified through the life stories fell into five categories. Coinciding
with the findings of Werner (1993), several participants discussed the importance
of having a support network to draw strength and acceptance from. The
importance of unconditional support and trust echoed through many of the life
stories:

Julia: My husband, he’s been behind me ever since I started. Poor
guy didn’t know I couldn’t read till his three year old nephew let the
cat out of the bag. His mother [sic] been reading the books to him
too long, so he knew when I was messing up the words. That’s how
they found out I couldn’t read.

When asked about the importance of inner strength and where she felt her inner
strength comes from Karen replied:

My husband. (laughs) Every time I got a problem he’s there and I
just go and we just talk about it for hours.

Mark describes his second wife as the person who helped shape who his is
today:

She was just a really nice person smart, everything I wanted, you
know, in a woman –really caring, very loving. Just somebody, you
know, would ah, help you along in life. She really helped me along,
I guess…I am a little, sort of, kinda different, but she kinda keeps
me grounded…And my wife, she’s probably—probably the only
person I’ve really ever trusted. I just been hurt so much through life,
um, and it’s taken a long time to build up any trust. But I think I
have a little bit of trust with her, you know, I think she’s the only one
I can trust.

In contrast to the middle-aged participants, the two young adult
participants referred to themselves more as loners, not having any specific
person as an intimate support. Social isolation may be the result of numerous
factors, but may also demonstrate for the younger participants another delayed
transition through Erikson’s stage of intimacy vs. isolation. As their current life focus is on career goals and academic pursuits, perhaps these two adults are still working through the challenges of constructing their identity.

In addition to using skills to manage difficulties, several participants referred to the coping by using their hopes and dreams to help them work through difficult life circumstances. Most of the hopes and dreams mentioned involved occupational pursuits such as “I wanted to be an artist” or “I would like to open up my own daycare.” However, not all of the participants referenced childhood or adult hopes. Several participants discussed having to abandon their lifelong ambitions when they discovered that their reading difficulty would prevent their dreams from materializing:

Julia: …When you’re with this—this dyslexia and don’t know it, you know you can’t go nowhere. You know you can’t be like everybody else, and you don’t know why, but you know you just can’t be like everyone else so I didn’t try. I worked in the factories.

Coinciding with hopes and dreams as a coping mechanism, four out of the eight participants referred to spiritual beliefs as a source of comfort and purpose during difficult times. One common idea noted in several of these life stories was the idea that “God is just not done with me yet.” The same participants stated that they continually hold on to the hope that regardless of their life circumstances; the situation always will improve. Spiritual beliefs also appeared to help adults create a context or a purpose for their difficulties. Believing that even struggles have an important purpose in their lives, several participants stated that a higher power helped to provide inner strength to meet life challenges.
Another common strategy to cope with lifelong reading struggles is using skills to buffer up weaknesses. Participants noted that listening, memorization and putting forth extra effort were tools in coping with reading struggles, especially in the employment realm. One participant noted that having to be independent and learn things on his own as a child was an advantage in his adult years as he had greater freedom to try a variety of occupations. The ability to find creative approaches to problems is also highlighted in the study conducted by Shessel and Reiff (1999). Participants referred to many of these strategies as “fighting through” or survival techniques. As mentioned in Chapter I, prior research studies also discuss the importance of self-awareness with regards to learning difficulties is important in the employment realm and other facets of life functioning. Again, the older participants provided more strategies for managing their difficulties as opposed to younger participants.

From an Eriksonian perspective, perhaps the internal awareness helps some adults prepare for opportunities and meet crises when they arise. However, a common issue running through many of the life stories was the difficulty of all of the participants to segment their life in terms of life transitions or stages. When asked to discuss the major turning points in his or her life, all but one of the participants referred to a series of difficulties or struggles. The idea “fighting through” life circumstances appeared often as a reply for coping with challenges. Phrases such as “I don’t know, I just did it, and I kept going” commonly appeared as responses. Furthermore, the lack of awareness to segment their own lives as a series of changes or growth is an important concept.
because one of the research questions at the start of this study was to examine what unique transitions adults with reading difficulties encounter. The inability to view their life as a series of stages or changes from childhood through adulthood prevents such an examination at this point in time. Only one of the participants, John, noted that all of the changes in his life have been positive ones and felt that his life was an “even plane” with nothing out of the ordinary to mention. Even though John described his life as positive changes, he was still unable to articulate his life in terms of transitions. Perhaps the participants are still facing challenges, and while still undergoing these internal struggles have had little opportunity for introspection. The life story may have been the first opportunity some of the participants have had to view their lives cohesively. Nevertheless, the point that all of the participants struggled with the same question, even when prompted, reveals that the area of life transitions with this population needs further study.

Given the struggles that the participants shared through their life stories, I was impressed by the fact that most adults had positive self-appraisals and a positive outlook on life in general. While many of the participants’ reflected feeling “like a dummy” or incompetent during the childhood and young adult years, those adults who have received more knowledge about the nature of their disability feel better about themselves as middle-aged adults. Several of the participants stated they were content with themselves at their current stage of life. Only the youngest participant expressed, “I don’t like myself very much.” As mentioned in the previous paragraphs, age may be a factor in the ability to
provide a better picture of the self. Having had more experience, and working through difficult circumstances may contribute to positive self worth. One of the reasons that this group of individuals may have higher feelings of inner strength and express more positive self-appraisals is that they are all enrolled in and sought out help in an organized tutoring program. The sample for this study included higher functioning students. This group of adults was unique in that they actively pursued help for their struggles. Project Learn provides one-on-one tutoring for its clients. Even without a formal diagnosis, participants may have more knowledge about their reading struggles by having individual attention to work through reading difficulties. Tutors are also trained to use individual strengths to buffer weaknesses. The current investigation did not examine the effects a positive learning environment would have on overall self-identity; however, five of the eight participants specifically referred to their Project Learn tutor as a source of help. Two other individuals referred to tutors in other academic settings.

Another factor that may contribute to overall positive self-appraisal statements is that most of the individuals in this study had positive support networks and used constructive coping methods. The commonalities between the four adults with more positive statements about themselves and life include: all were at least twenty-five years old; all had at least one person in their lives to provide unconditional support; all were employed or had been employed for an extended period of time; all had a positive outlook on overcoming difficulties. Werner (1993) cites several groups of protective qualities for the learning
disabled adult such as the temperament of the individual, personal skills and beliefs, parenting styles within the household, network supports such as family and mentors, and windows of opportunity in the individual's life. As one can see, several of the factors discussed in the Werner study apply to the individuals in this study. Furthermore, Werner also discusses another positive quality of life, and that is spirituality. All of the participants with higher self-appraisals in this study either cited their spiritual beliefs as the backbone to their positive outlook or the idea that difficulties are only a short-lived part of a larger picture. As Mike comments:

   It just takes a lot to get me, um get me going. I mean, I always looked at the brighter side of things, I never worry about anything. I ignore all the stress in my life. If it doesn’t go right, then screw it. Oh well.

   Additional factors that may contribute to the preservation of the self through life challenges and opportunities are the obstructive coping strategies utilized by most of the participants at some point in their lifespan. Categorized as ways of “insulating the self,” there were six strategies that participants used to protect their ego development: isolation, avoidance, introversion, escapism, abandonment of dreams, and repression. Several of these protective tactics have been recorded throughout the learning disabilities literature. The participants described using strategies such as isolating themselves from friends or avoiding difficult circumstances, specifically challenges that involve reading, as a way to overcome difficulties. One of the more noteworthy findings in this study that coincides with learning disabilities research is that four participants discussed
using strategies of “insulating the self” as a means of hiding their difficulties from others at various points in the lifespan. By hiding their difficulties, participants also repressed their abilities. Julia referred to hiding her difficulties as “playing the game.” Jack discussed the idea that no one really knows him. Karen also explained how she managed to hide her disability from her husband.

Karen: Well, I would not be where I am at right now. I would be at (local grocery store) working like night stocker. I would not be there. If I knew—if I was like a normal person, you know. I—as far as me and my husband I think I would still be with him cuz he didn’t know my problems until after we were married like seven years. Oh yes. I hid it.

Interviewer: Why did you hide it from him?
Karen: It’s embarrassing. Not knowing and I know now a lot more then I did back then.
Interviewer: How did he find out?
Karen: He found out when I couldn’t help the kids with their homework.
Interviewer: And then, and then what happened?
Karen: I think I shocked him. When you play it out so many years, you get good at it (laughs), you know. I mean.
Interviewer: So what did you do, how did you-how did you—
Karen: He told me to go back to school, and I did go back to school. But it was just too hard. Took time, and I had to work part-time and then the kids and then school, it was just too hard. But I did try quite a few times to go back to school. How did I hide it? I hide [sic] it by not mentioning it. I would never mention it. I would like-back then you didn’t have checks that you have to write out, you always paid with cash.

Shessel and Reiff (1999) refer to this behavior as the “imposter syndrome,” and state that some adults with learning disabilities feel unworthy of their successes, as though they did not deserve their accomplishments. Also, Shessel and Reiff point out that the anxiety associated with the imposter syndrome can work to inhibit potential success. Furthermore, repressing memories or abilities may also prevent an individual to see his life as a series of transitions as there may be key points of crisis that are psychologically repressed. The category of insulating the
self demonstrates the emotional side of reading struggles and provides greater insight about the challenges adults face in preserving their inner sense of self.

In summary, the previous chapter reveals that the participants in this study demonstrate resiliency through their lives. In response to the first research question as to contributing factors that led to positive or negative life experiences, the participants revealed that family dynamics were not a significant factor in terms of life outcomes, but families do contribute to styles of coping strategies utilized. For example, Mike, who came from an unsupportive, violent family background demonstrated the same level of adult success as John, who came from a supportive family background. Furthermore, families contribute to providing resources and life opportunities. Support networks were also a factor that contributed to positive life outcomes. The participants in this study showed that they could adjust to negative experiences provided there were opportunities to obtain employment success and have unconditional support from at least one person in their lives.

In response to the second research question as to the pervasiveness of the theme of reading struggles in the life stories of individuals with reading struggles, all of the participants referred to difficulties with reading or academics since early childhood. The theme of reading struggles was indirectly linked with many other topics throughout the narratives. For example, most of the middle-aged and older participants spent most of their narratives discussing employment and their family life. Indirectly they would reference how their reading struggle influenced occupational attainment and interpersonal relationships. The younger
participants referred to their reading struggles more often as a larger portion of their narratives related to schooling. Overall the theme of reading issues was more prominent during questions that involved early life transitions such as schooling and family experiences. The other point in the lifespan when middle-aged adults referred to the aspect of their own reading struggle is when discussing their own children's educational attainment. All of the adult participants with children discussed the importance of making sure their children completed their education.

As discussed throughout the previous chapter, Erikson’s (1950) lifespan model provides the framework for examining the lives of individuals with reading struggles. Through the use of this model, I was able to see the manner in which the participants' stories fit together as a collective whole. Overall, the participants revealed that they face the same transitional tasks that Erikson noted we all face in our society. However, what may be unique to adults with reading struggles is the timing and progression of passing through Erikson's stages. Adults with reading struggles may be delayed in gaining of sense of industry and face the added struggle of identity development during their young adulthood. The life stories show that late adolescence and early adulthood are critical times of transition. Unfortunately, some of the participants also repressed memories associated to this phase of development.
CHAPTER V

CONCLUSION

The final research question asked what insights could be gained regarding the emotional, familial, and social aspects of adults with reading struggles. While the current study consisted of a small sample size therefore limiting the ability to generalize, I believe the findings revealed through the participants’ life stories adds to the current body of knowledge and can contribute to future theoretical development. In between the lines of their stories, the participants collectively demonstrated that reading struggles permeate into all aspects of their lives affecting academic, occupational, and interpersonal attainments.

While primarily believed to be an academic struggle, the life stories shared through this study show that difficulties with reading can have a variety of emotional consequences. Participants shared feelings of anxiety, frustration, and loneliness during the life journey. The participants’ viewed their lives as a continual series of challenges. In this context, reading was just another struggle. However, in the face of very difficult life circumstances, all of the participants except for Jack, who is still in college, managed to balance work responsibilities with family. For example, Mark, who shared one of the most traumatic experiences concerning his violent home life as a child, managed to rise up from poverty and abuse. He admits that he still has nightmares about some of his life
experiences, but he still feels that, "I think I need ah, a struggle. I need ah, I need pressure. It makes me a better person."

The emotional experiences shared by the participants with reading struggles revealed resiliency and inner strength. The most sensitive time for emotional struggle during the lifespan appears to be late adolescence and early adulthood. Jack appeared to exhibit great difficulty in coping with feelings of inadequacy and sharing meaningful interpersonal contact with others. Practitioners working with this population need to address emotional difficulties as well as reading struggles. On a positive note, this study demonstrates that adults can rise above their circumstances and still manage to have an overall positive self image. Future research needs to examine the variables that contribute to resiliency in adults with lifelong reading struggles as well as examine the implications of insulating the self over the lifespan. One question that arose through examining the emotional aspects of reading struggles was—Does insulating the self inhibit the development of talents or strengths and key points in the lifespan? Could this inhibition prevent important life opportunities?

Creating strategies for adults to become aware of, cultivate, and demonstrate unique strengths should continue to be a focus of intervention programs. Furthermore, helping adults with reading struggles develop and utilize constructive coping mechanisms may aid in facing emotional challenges associated with reading difficulties.

In addition to the individual implications of reading difficulties, the participants’ shared a host of familial factors that influenced their ability to face
life’s challenges and opportunities. Several of the participants came from family backgrounds of poverty and neglect, yet as I listened to the participants’ life stories, these individuals were able to find meaning and come to a point of peace with their early life circumstances. Furthermore, support systems appeared to be a positive buffer to the negative emotional aspects of reading struggles. Specifically, siblings and spouses were referred to more often as being primary sources of support. The strong connection between siblings mentioned in several of the life stories contrasts Erikson’s view that siblings tend to compete for parental favor (1980). There has been little current work in the field of reading disabilities examining the impact of sibling relationships or spousal relationships throughout the lifespan. The current focus in working with adults with reading struggles is academic remediation; however, understanding qualities of important support networks may help practitioners in the future to create better support groups or provide individuals with reading struggles emotional supports for coping. Additional research is needed in finding the most effective way of helping the individual within the context of the family.

From a societal prospective, the current study brings to light several key issues for the field of reading disabilities. The topic of diagnosis has been discussed in numerous articles in the field of learning disabilities. While the general assumption would be to provide remediation early in development, the exact timing and process for achieving the greatest benefit has yet to be determined. The current study adds to the body of research that supports early awareness of personal strengths and weaknesses. From an Eriksonian
perspective, early awareness of internal resources can be empowering and help
the individual to meet life’s challenges and opportunities. However, the current
study also raises the question- Does early diagnosis inhibit lifecycle transitions?
Of all the participants’ stories regarding their feelings about early school
experiences, the two youngest participants, who had early intervention and
remedial support for most of their schooling years, expressed disliking their
school experiences the most. Given all the current support, resources,
legislation, and knowledge, these individuals described their experiences as the
same or worse than the other participants. Clearly, while great strides have been
made in the field of reading and learning disabilities, there are still many issues
that need to be investigated further. Because learning disabilities have been
estimated to influence the lives of approximately fifteen percent of the population,
this topic is relevant.

Even in the face of the limitations of this study, the current investigation
provides insight into the lives of adults with reading struggles from their own
perspective. Future research will need to compare the life stories of adults with
reading struggles with adults without reading difficulties. Also, for this study, there
was insufficient time to assess gender differences between participants;
however, several differences between the life perspectives of the men and
woman were noted. From Erikson’s perspective, as a society one of our current
transitional crisis involves providing an educational system that can help propel
individuals to meet their inner potential. Overall, the current study can contribute
to the understanding of the adult learner as a whole person and provide insight
as to where we are as a culture. The participants shared with me a motivation to help others. Their hope was that their life stories would have an impact in sparing others some difficulty along life’s way. In between the lines of their life stories, the participants’ revealed struggles, but I was impressed by their stories of triumph. As a society, our responsibility is to listen and to continue searching for answers. There are still stories of adults with greater reading and life struggles that need to be evaluated. Without addressing the needs of individuals with reading and learning struggles we risk being a culture unable to transcend beyond the early stage of industry versus inferiority.
REFERENCES


APPENDICES
APPENDIX A

IRB APPROVAL LETTER

Office of Research Services and Sponsored Programs
Aurora, OH 44252-2102
330-972-7100 Office
330-972-6261 Fax

June 15, 2006

Sophia A. Brdarz
Family and Consumer Science
The University of Akron
 Akron, Ohio 44325-1103

Ms. Brdarz:

The University of Akron’s Institutional Review Board (IRB) completed a review of your application for continuing review entitled “In Between the Lines: A Personal Look at Lifelong Reading Struggles”. The IRB application number assigned to this project is 2004009-1.

The protocol qualified for Expedited Review and was approved on June 13, 2006. The protocol represents minimal risk to subjects and matches the following federal category for expedited review:

(7) Research on individual or group characteristics or behavior or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies

This approval is valid until July 1, 2007 or until modifications are proposed to the current project protocol, whichever may occur first. In either instance, an Application for Continuing Review must be completed and submitted to the IRB.

Enclosed is the informed consent document, which the IRB has approved for your use in this research. A copy of this form is to be submitted with any application for continuation of this project.

Please note that within one month of the expiration date of this approval, the IRB will forward an annual review reminder notice to you by email, as a courtesy. Nevertheless, please note that it is your responsibility as principal investigator to remember the renewal date of your protocol’s review. If your project is funded, failure to comply with IRB requirements could jeopardize your continued funding. Please submit your continuation application at least two weeks prior to the renewal date, to ensure the IRB has sufficient time to complete the review.

Please retain this letter for your files. If the research is being conducted for a master’s thesis or doctoral dissertation, you must file a copy of this letter with the thesis or dissertation.

Sincerely,

[Signature]
Sharon McWhorter
Interim Director

Cc: Pamela Schultz, Advisor
Department Chair
Phil Allen, IRB Chair

The University of Akron is an Equal Education and Employment Institution
APPENDIX B

INFORMED CONSENT FORM

RESEARCH STUDY DESCRIPTION:
You are invited to participate in a study being conducted by Sophia A. Brdarski, a Masters level student from the School of Family and Consumer Sciences, College of Fine and Applied Arts, University of Akron, Akron, OH.

This project focuses on the life stories of adults who have experienced lifelong reading difficulties. Specifically, the project will look at information about the experience of living with a reading difficulty. If you decide to participate, you will be asked to take part in an interview at a convenient time and place for you. The interview should take approximately 2 hours of your time. Participation in the project is completely voluntary.

RIGHT TO REFUSE OR END PARTICIPATION:
You may refuse to answer any questions and may withdraw from the study at any time without penalty.

CONFIDENTIALITY:
Your confidentiality will be protected throughout the study. Any data obtained from you through audiotapes of interviews will be kept confidential and will not be viewed by anyone but the researcher. The identities of individual participants will not be revealed during presentation or write-up of findings. Pseudonyms will be used in conjunction with direct quotes. Data will be carefully stored for 5 years from the date of publication and then destroyed.

RISKS AND BENEFITS:
There is no obvious medical or emotional risk involved in this study. However, there is always the possibility that sensitive feelings may be evoked through discussing one’s life story. If you would like to discuss your feelings about issues discussed in the interview you may contact Diane Morawski, Director of Project Learn for a debriefing session free of charge. If you feel that additional counseling is needed, you may be referred to the Clinic for Individual and Family Counseling located at The University of Akron 330-972-6822. The Clinic offers reduced fees on a sliding scale basis for persons seeking individual and family counseling. The Clinic does not turn anyone away based on income levels.

If you have any questions about this research project, you can call me at 330-592-4783 or my advisor Dr. Schulze at 330-972-7725.
Once the project is complete you will receive a copy of your life story interview to keep. This research project has been reviewed and approved by The University of Akron Institutional Review Board for the Protection of Human Subjects. Questions about your rights as a research participant can be directed to Ms. Sharon McWhorter, Associate Director, Research Services, at 330-972-7266 or 1-888-232-8790. Thank you for your participation!

**I CONSENT** to participation in this project:

Name of Participant (Please PRINT)  Date

________________________________________________________________________

Signature of Participant  Signature of Interviewer

**I GIVE MY CONSENT** for the interview to be audio taped:

Name of Participant (Please PRINT)

________________________________________________________________________

Signature of Participant  Signature of Interviewer
APPENDIX C

LIFE STORY QUESTIONNAIRE

*Life Story Questionnaire (Adapted from Atkinson, 1998)*

**Script:** You have been asked to be part of a research project looking at the lives of individuals with lifelong reading struggles. I would like to ask you some open ended questions about your life experiences. Remember that any information you provide will be kept confidential and any names said during the interview will be changed to protect privacy. You can choose to skip any questions or stop this interview at any time.

**Demographics:**

*Male/ Female: __________
Age: ____
Occupation: _______________________________________________
Recreational Hobbies: ______________________________________
_________________________________________________________
_________________________________________________________
*Number of years of schooling completed:________________________
Marital status:_____________________________________________
Number and ages of children:________________________________
Life Story Questionnaire (Adapted from Atkinson, 1998)

Note: Questions in brackets serve as follow up prompts to aid in responses.

Questions:

1. How would you describe your parents’ personality & emotional qualities?  
   [did you get along with your parents?]

2. What was growing up in your house or neighborhood like?  
   [what was this cultural setting like for you?]

3. As a child or youth did you feel encouraged to try new things or did you feel held back?

4. What were some of your struggles as a child?

5. What are your best memories of school?  
   [Did you have any favorite teachers? OR What accomplishments in school are you most proud of?]

6. What are your worst memories of school?

7. Did you have any dreams or ambitions as a child or teenager?  
   [Did you achieve what you wanted to or did your ambitions change?]

8. What major transitions or turning points did you experience as a teenager? as an adult?

9. What social pressures have you experienced as an adult?

10. What has been the most important lesson in life, outside of the classroom?

11. Did you ever have any doubts about achieving your goal(s) in life?

12. How did you end up in the type of work you do or did?

13. What is important to you in your work?  
   [Has work been satisfying or something you had to put your time into?  
   What comes the easiest in your work? What’s the most difficult?]

14. Do you currently have a spouse or partner?
[If no, have you ever...?]
[What was it about him/her that made you fall in love? OR What does intimacy mean to you?]

15. Do you have children? If so, what values and lessons do you try to impart to your children?

16. Do you feel that you have inner strength? Where does that come from? [OR In what ways do you experience yourself as strong?]

17. Who shaped and influenced your life the most?
[Who are your heroes & heroines? Who helped you develop the current understanding of yourself?]

18. How have you overcome or learned from your difficulties?

19. How would you describe yourself at this point in your life?

20. What matters the most to you now?

21. What time in your life would you like to repeat?

22. What are some things you hope you never forget?