Dyslexia and the Life Course

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Abstract

The life stories of adults diagnosed with dyslexia as children were examined, with emphasis on the related emotional experiences. The life story method of narrative analysis was used to compare and analyze the accounts of 12 participants who were interviewed extensively. The findings indicated that self-esteem problems may emerge by early childhood as individuals contend with aspects of their learning disabilities that interfere with typical development. By school age, all participants noted self-esteem problems when they experienced struggles or failures in school, which could feel traumatic. Testing and diagnosis improved self-esteem when conducted in a relevant manner that led to adaptation. The central plots of the participants’ lives were characterized by the interplay between the functional challenges of their learning disabilities and the related self-esteem issues. Compensation involved the individual’s areas of competence and the resources within the environment. Niches in late adolescence and young adulthood held potential to dramatically improve compensation. Participants generally exhibited four ways of life in adulthood and an added sense of emotional insecurity. Each attempted to integrate lifelong emotional experiences related to living with diagnosed dyslexia.

The first generations of individuals formally diagnosed as children with neurologically based, developmental reading disorders that meet the criteria for dyslexia are now adults who are able to reflect on their experiences over the course of life. Few studies are available in the professional literature that describe the specific emotional issues related to this experience from the perspective of individuals with this learning disability. The purpose of the present study was to capture the common aspects of the emotional story over the life course of persons who lived it and to discover significant differences between the stories based on circumstances and resources. Understanding how this story can unfold holds potential to help parents and professionals intervene in a more sensitive, supportive, and effective manner.

Literature Review

A void exists in the literature concerning the emotional experiences related to living with diagnosed dyslexia over the course of life. Studies on adaptation and personality characteristics at best provide useful leads to begin to explore the related emotional issues. Mostly case-based and theoretical in nature, the psychotherapeutic research builds on that exploration. A few innovative, qualitative studies attempt to describe pertinent aspects of the emotional experiences of living with a learning disability. Only one qualitative study (Hellendoorn & Ruijsemaaars, 2000) specifically focused on the experiences of individuals diagnosed with dyslexia and the related adjustment issues.

Adaptation

The studies regarding adaptation (Ambruz, 1990; Arjävärvi & Arjävärvi, 1983; Haufrecht & Berger, 1984; Rawson, 1977; Scott, Scherman, & Phillips, 1992) confirm that identification and intervention promote understanding of learning disabilities and facilitate better academic and vocational outcomes. However, Gottfredson, Finucci, and Childs (1983), in a follow-up study of nearly 600 graduates from a school for boys with dyslexia between 1940 and 1977, found that even with extraordinary societal and educational resources, individuals with dyslexia were more likely to achieve less than their parents and peers with similar socioeconomic means and levels of intelligence. Although dated, the findings of this study are relevant and sobering and illustrate the potential negative impact of the disorder on academic and vocational achievement even under optimal circumstances.

Many studies have noted that psychological interventions that focus on low self-esteem coupled with academic remediation (Ambruz, 1990; Haufrecht & Berger, 1984; Rawson, 1977; Scott et al., 1992) appear to be the most successful method to help individuals cope and adapt. Haufrecht and Berger (1984) reviewed cases over a 10-year period from a program that involved academic remediation and individual and family therapy and found that the interventions served to complement one another. Scott et al. (1992) studied successful adults with dyslexia and found that the keys to success appear to be early intervention, encourage-
ment of talents and hobbies, good family support, and involvement in the search for self-worth. All of these findings indicate the necessity for remediation in conjunction with psychological interventions to promote adaptation and achievement.

**Personality Traits**

The studies that focus on personality traits are only in the infancy stages. Findings are inconclusive. Self-esteem and self-confidence appear to be affected in a negative way (Casey, Levy, Brown, & Brooks-Gunn, 1992; Kosmos & Kidd, 1991; Plaisant, 1989). Although Plaisant (1989) found that no clear-cut personality profile emerged from the responses to questionnaires of 145 adults with dyslexia, the findings implied that such adults have a more negative than positive self-concept. Kosmos and Kidd (1991) found that individuals with dyslexia tend to have more dependent personality characteristics than their peers. An additional study found that such persons are more likely to exhibit symptoms of anxiety and depression as well as low self-esteem and a negative self-image (Feldman et al., 1993).

A major quantitative study revealed that specific reading impairments are not associated with emotional difficulties (Lamm & Epstein, 1992) and that individuals with reading difficulties are no more likely to exhibit psychopathology than the general population. This study dispels a longstanding societal bias that specific reading impairments are the result of emotional problems. However, it does not describe the emotions that are associated with living with this type of learning disability. Much remains to be learned about the feelings and personality traits involved.

**Psychotherapeutic Literature**

In their clinical reports, psychoanalytic thinkers (Kafka, 1984; Migden, 1990; Palombo, 1985, 1987, 1991, 1993, 1994, 2001; Shane, 1984) have affirmed the need for simultaneous attention to learning difficulties and emotional issues. In extensive case-based research and theoretical work, Palombo (1985, 1987, 1991, 1993, 2001) found that an awareness of the learning disabilities involved on the part of caregivers is essential to help children function in school and in other important areas of their lives. Awareness, sensitivity, and action on the part of the caregiver foster the process of compensation at both functional and psychological levels within the child.

Compensation on a functional level involves helping the child to develop cognitive strategies to bypass the effects of the deficit or to enhance functioning by using areas of strength to make up for cognitive limitations (Palombo, 2001). Compensation on a psychological level refers to helping the child manage the stigma and feelings related to experiencing difficulty and failure with learning that negatively affect self-esteem. Development of the personality or sense of self is largely influenced by how well the child is able to function in areas affected by the disorder. Chronic functional difficulties appear to result in low self-esteem, which is the most common psychological problem for persons with dyslexia (Palombo, 2001).

Palombo (2001) theorized that individuals with learning disabilities develop self-narratives. Self-narratives are stories that persons tell themselves to make sense of their emotional lives and subjective experiences. For persons with learning disabilities, self-narratives involve each individual's personal explanations of what having a learning disability means and reflect any related emotional concerns. For individuals with dyslexia, self-narratives tend to be characterized by low self-esteem. Self-narratives involve various levels of acceptance or denial of the learning disabilities at play and may be positive or negative, depending in large part on the person's ability to compensate, functionally and psychologically, while living with the disorder.

Significant and effective attention to functional concerns by caregivers appears to promote adaptation, positive self-esteem, and positive self-narratives, resulting in success in areas of difficulty and acceptance of the learning disability (Palombo, 2001). Insufficient attention to functional concerns can result in poor adaptation, low self-esteem, and negative self-narratives. Under those circumstances, an individual is ostensibly more likely to deny or even disavow the learning disability. Denial refers to consciously rejecting the diagnosis while realizing that a problem exists, but minimizing it or attributing it to alternative explanations. Distraction is a more severe form of denial where something (in this case, the learning difficulties) is seen but not conceived (Siegel, 1996). Persons with learning disabilities—diagnosed or undiagnosed—may employ either or both of these defense mechanisms to protect self-esteem due to the experience of failure and to fears of being identified as or feeling "lazy," "stupid," "crazy," or even "mentally retarded." The role of caregivers, such as parents and professionals, is to help persons with dyslexia function, adapt, and compensate and to encourage positive self-esteem and self-narratives.

**Ethnographic Studies**

Recent ethnographic studies that focus on the perspective of individuals living with learning disabilities (Gerber & Reiff, 1991; Hellendoorn & Ruissemaars, 2000; Orenstein, 2000; Reiff, Gerber, & Ginsberg, 1997) further illustrate the experience. These studies have confirmed that individuals were well aware of struggles with learning in their school experiences and throughout life. Gerber and Reiff (1991) found that the extent to which persons were able to adapt depended on the nature and severity of their disability and on the systems of accommodation that were developed. Successful adaptation led to an overall improved quality of life, except for the highly successful group, who experienced less social and
emotional satisfaction than the moderately successful. This finding may speak to the social and developmental costs of the pursuit of success, particularly during adolescence or other stages of life.

Orenstein’s (2000) study specifically examined the process of living with an undiagnosed learning disability that is later diagnosed, illustrating the resulting sense of frustration, shame, loneliness, and low self-esteem. She coined the term “the chasm,” which describes a common phenomenon that individuals experience throughout life when they are unable to perform activities expected of peers due to undiagnosed learning disabilities. Hellendoorn and Ruijsenaars (2000), in a follow-up to Gerber and Reiff’s (1991) study, interviewed 27 Dutch adults ages 20 to 39 who were diagnosed specifically with dyslexia as children. They found that most participants were very aware of the difficulties related to their learning disabilities well into adulthood. Even though participants reported social and emotional problems, they still perceived themselves as persevering and responsible. More than half noted feeling “different” and having “difficulty with social contacts.” They felt as if others could not empathize with their experiences. They felt uncertain as adults. Some also reported that they had few friends and were “socially awkward.” Those with positive elementary school experiences were more accepting of their disability.

Gerber and Reiff’s (1991); Reiff et al.’s (1997); and Orenstein’s (2000) studies focused on the general experience of living with a learning disability rather than on the specific experience of living with diagnosed dyslexia. More research is needed to determine how their findings apply to the experiences of persons diagnosed with dyslexia. These studies also, by design, highlighted specific aspects of the experience. The interview processes were somewhat structured. In their earlier work, Gerber and Reiff (1991) focused on a number of central sociological factors. In their follow-up study, Reiff et al. (1997) examined the issue of success among persons with learning disabilities. Orenstein (2000) explored the emotional process one experiences when having an undiagnosed learning disability diagnosed in adulthood. Hellendoorn and Ruijsenaars (2000) specifically examined emotional experiences related to living with dyslexia, with an emphasis on adjustment modeled after Gerber and Reiff’s (1991) work.

Conclusion

As the literature concerning the emotional experiences of individuals with learning disabilities is so sparse, individuals’ spontaneous reflections on their lives over time appeared to potentially offer valuable information. Rather than approaching the study with a specific set of questions or variables, a more open-ended inquiry into the events and emotions related to living with diagnosed dyslexia over the course of life was thought to be a useful way to authentically articulate participants’ experiences. Ascertaining the life story from the perspective of those who lived it would begin to provide a survey of the emotional issues involved and their interrelationships, resulting in valuable practical information and leads for future research.

Method

Focus of the Study

This study addressed the question “What are the life stories of adults who were diagnosed with dyslexia as children?” The researcher held that a systematic study of the life stories of such individuals would result in a survey of the emotional issues connected with living with diagnosed dyslexia over the course of life. He held that even when a learning disability is diagnosed, a unique set of emotional experiences ensues that involves living over time with a hidden phenomenon that is prone to misunderstanding. He held that focusing on dyslexia rather than on the broader category of learning disabilities would help to begin to distinguish the emotional aspects of living with this learning disability from the experience of living with others.

Research Design

The life story method of narrative analysis as outlined by Atkinson (1998) was used in the research design. This method of qualitative research is used to articulate the experience of a genre (Atkinson, 1998; Corradi, 1991; Reissman, 1993) describing the qualities within a type of life in a manner that is accurate, relevant, and compelling as determined by those who are familiar with it. The life story method is different from the anthropological method of life history, which is a single-subject design involving the study of one individual’s life over time (Atkinson, 1998). In contrast, life story refers to the study of a phenomenon experienced by many individuals through comparing and contrasting the accounts of their lives.

Each participant in the study was interviewed. His or her story was recorded on audiotape and transcribed. The researcher then created a story based on the transcript that was in the participant’s words. Participants reviewed, edited, and supplemented their stories to ensure accuracy in follow-up interviews. To determine common and contrasting elements of the shared story, the researcher eventually compared all accounts collected with one another and created a typology into which all cases fit and became a collective story. Available participants reviewed the collective story to ascertain whether it was an accurate, relevant, and compelling depiction of the experience. Corradi (1991) referred to the participants’ review of their stories and the collective data as the “self-validation circle” (p. 112), which is similar to the member check process associated with the grounded theory method (Glaser, 1978). The researcher
integrated the participants’ feedback into the findings. Representatives of the wider community who were familiar with the experience but who did not participate in the study then reviewed the collective story. This part of the process involves breaking beyond the circle of self-validation to determine the accuracy, relevance, and compelling nature of the findings from the perspective of the wider community affected by the phenomenon (Corradi, 1991). Feedback from this second group is also in the final report.

**Recruitment Techniques**

Twelve individuals who were diagnosed with dyslexia prior to age 14 were interviewed extensively. They responded to an advertisement for the study circulated at the 1998 Illinois conference of the International Dyslexia Association, to an announcement placed on the Web site of the national office of the same association, or to advertisements in colleges and mental health centers. Others, including professionals or family members who had seen advertisements or heard about the study, also referred potential participants.

**Screening of Applicants**

All participants were diagnosed prior to age 14 with learning disabilities in the area of reading through observation or testing by professionals within school systems. At the time they were diagnosed, alternative labels were commonly used to describe dyslexia, such as minimal brain dysfunction or reading learning disability (Hallahan, Kauffman, & Lloyd, 1985). A review of each participant’s symptoms supported a diagnosis of dyslexia as defined by Pennington’s (1991) criteria.

Pennington (1991) defined the primary symptoms of dyslexia as problems in reading and spelling due to difficulty with the phonological coding of written language. He noted correlates between dyslexia and problems in language processes (i.e., articulation, naming, and verbal, short-term and long-term memory). Secondary symptoms—meaning those symptoms that are a cause of core and correlated symptoms—can include poor reading comprehension, poor math, poor self-esteem, letter reversals, and eye movement differences in reading. Problems with attention, delinquency, and visual-spatial perception are also noted as sometimes associated with the disorder, but with no causal relationship.

A checklist was developed and administered by the researcher under the supervision of a licensed clinical psychologist using the symptoms Pennington (1991) described at various stages of life. It is presented here in narrative form. Childhood symptoms include problems with learning the alphabet, letter names, phonics, and math facts. Adolescent symptoms include slow reading speed, poor performance on timed tests, and difficulty with completing homework. Possible emotional problems in childhood and adolescence could include anxiety and depression, reluctance to go to school, physical complaints leading to avoidance of school, and fear of failure in school. Symptoms that may be experienced throughout school and into adulthood include difficulties reading aloud, difficulties with spontaneous spelling, slow reading or writing speed, letter and number reversals, and unusual reading or spelling errors. Adult manifestations can include problems with reading, language, spelling, articulation, name finding, and verbal memory (phone numbers and addresses).

All participants reported problems with phonics in childhood. Some had difficulty remembering the process of learning the alphabet, letter names, or math facts and could not report on these symptoms. All acknowledged all three of the adolescent symptoms (i.e., slow reading speed, difficulty completing homework, and poor performance on timed tests). All acknowledged at least one of the emotional problems listed in childhood and adolescence. All had symptoms that were experienced throughout school and into adulthood, at least in the areas of reading and spelling. All had adult manifestations of their disorders in some form, at least involving slow reading. The checklist was used to ensure that the reported symptoms over the course of life were consistent with dyslexia. A more sophisticated diagnostic process was thought to be beyond the scope of this study, which focused on the life story and the general emotional issues of individuals who identified themselves as having been diagnosed with dyslexia or with neurologically based reading disorders that meet the criteria for dyslexia during childhood (see Limitations section).

**Characteristics of Participants**

Participants ranged in age from 25 to 45. The average age was between 33 and 34 years old. Eight of the participants were men, and four were women. All were European American, and one was also African American. Most came from middle class backgrounds, although two had extraordinary financial means. Most attended mainstream schools, although three had studied at high schools for persons with dyslexia. Ten lived in the Chicago area. One lived in Canada, and another in a city on the West Coast of the United States. All had completed high school. Eight finished college. Two also had graduate degrees. In adult life, three participants had started highly successful businesses. Three held professional positions. Six worked in para-professional capacities. A synopsis of each participant’s story, including additional relevant demographic and descriptive information, is presented in the Findings section of this article to establish a context for the collective story. Although demographic and descriptive data are usually presented in the Method section, the researcher was concerned that separating that information from the participants’ stories would make them seem disjointed. He also felt that repeating these data in two sections would be redundant.
Data Collection

Individuals told their stories over the course of one to two meetings with the researchers. Ten were interviewed in their homes or in the researcher’s office, depending on their choices. Two were interviewed by phone, as they lived out of state and were included because their stories represented unique aspects of the experience and lent diversity to the sample. (One had attended a high school for persons with dyslexia and the other was from a bilingual city.) Total initial interview time with each individual was between 1½ and 2½ hours. All interviews were tape-recorded and transcribed. Individuals reviewed their transcripts to ensure accuracy and gave additional input in follow-up interviews that lasted an additional 1½ to 2½ hours. Total interview time with each participant prior to reviewing the results of the study was 3 to 5 hours. Final transcripts equaled approximately 25 single-spaced pages per person, for a collective total of 300 single-spaced pages.

Data Analysis

Using the life story method, the transcripts were compared to one another. In this method, the way in which data are interpreted depends on the nature of the stories collected, with the ultimate goal of presenting the depicted experience in a manner that is accurate, relevant, and compelling, as determined by those who told their stories, those familiar with the experience who reviewed the findings, and others who would benefit from the information. To this end, a variety of analytic and interpretive methods may be used (Reissman, 1993). In contrast to other types of narrative analysis, because the unit of study is the story, the life story method does not necessarily focus on overarching themes.

As the participants’ final transcripts were reviewed, the researcher felt that preserving the elements and the unity of the story was essential to be able to provide a cohesive depiction of the events and emotional experiences over the course of life and their meanings and interrelationships. This approach is consistent with Atkinson’s (1998) emphasis on seeing the story first and recognizing “how the structure and its elements (plot, beginning-middle-resolution, characters, and their roles) fit together and create an interactive whole with each other that provides the basis for understanding the story in its parts and as a whole” (p. 68). All stories collected involved shared experiences and dilemmas. Simultaneously, significant variations between stories dependent on each individual’s circumstances and resources were identified.

Consequently, Atkinson’s (1998) framework was used to examine the structure and the elements of the story. Prince’s (1987) definitions of elements of stories adapted for narrative analysis from Aristotle’s Poetics were used within this framework to further specify and define the elements to be observed and capture the participants’ shared experiences and dilemmas over the course of life. The elements included prologue, exposition, complication, plot, subplot, resolution, and epilogue, which will be defined as the findings are presented. This model captured the common elements of participants’ stories while simultaneously accounting for diverse outcomes. Four adulthood ways of life (Ruth & Oberg, 1996) were identified that involved predominant approaches to addressing functional and emotional issues into adulthood. Glaser’s (1978) concept of saturation was employed; as the data were analyzed, interpretations were made and revised until all cases were consistent with the framework of the final typology (see Note).

Consistent with the life story method (Corradi, 1991), the findings were reviewed in feedback sessions. These actions are considered qualitative measures of internal and external validity and helped to determine the accuracy, relevance, and compelling nature of the common story with variations (Atkinson, 1998; Corradi, 1991). Nine of the 12 participants reviewed the results. Three were reportedly unavailable at this stage. However, a review rate of 75% is considered very high. Revised with their feedback, the results were then reviewed at the 1999 International Dyslexia Association Conference in Chicago in an interactive poster presentation by others who were familiar with the experience but who had not participated in the study, such as persons with dyslexia, parents, and professionals. Approximately 75 individuals viewed the findings over a 2-hour period.

Both groups stated that the common story with variations generally described the emotional experience and pertinent ways in which the story can unfold. They suggested one modification during early childhood, which will be described in the Findings section. All who reviewed the findings appeared emotionally moved that others had in some way shared their experiences with a phenomenon that at best remains somewhat hidden to others. Such statements were made as “I remember that,” or “I’ve heard that before.” A number of persons attempted to situate themselves or someone they knew in one of the described ways of life. At the conference, one woman who was diagnosed thanked the researcher for presenting “a view from the other side.” Input from the two groups of reviewers was incorporated into the final common story with variations.

Researcher’s Experience During the Study

Participants were initially enthusiastic about interviewing for the study, most noting that they had always wanted to discuss the experience. After they reviewed the transcripts from their first interviews, however, they appeared self-conscious. Consequently, the researcher did extensive outreach via phone calls to schedule the follow-up interviews. In those interviews, participants had to be assured that their stories were articulate and worth telling.
Whereas the self-consciousness observed in the interview process could, in part, be explained by the effect of seeing one's spoken word in writing, it also seemed reflective of the participants' sense of isolation with the phenomenon and consequent concerns that their stories would be misunderstood. They seemed to feel that they would not be believed or that the accounts of their lives would make them appear less than their actual competence or intelligence. Also, telling their stories at times was simply a painful process.

Meetings to review the collective story and ways of life were usually met with a sense of understanding and relief. However, three participants were unable to review the results at that stage, reportedly due to schedule conflicts. These individuals exhibited various signs of self-consciousness that may have contributed to their declining to participate in this final part of the process, which was optional. The individuals who were able to review and comment on the findings consistently and uniformly reported that they felt validated that their hidden experiences had been shared and articulated by others.

Findings

This section is organized into two parts. Synopses are presented in the first part to familiarize the reader with each participant's story. They also provide a context to better understand the collective story and ways of life, which are presented in the second part. Names of participants and prominent figures in their lives and, in some cases, participants' occupations have been changed to ensure privacy. When an occupation was changed, a comparable occupation was substituted that was reflective of the individual's level of education and achievement.

Synopses of Participants’ Life Stories

Tommy is a 38-year-old, married European American man and a father. He is a highly successful leader in the field of industrial design. In early childhood, he noted that others were often concerned about his difficulties with spoken language. He remembers them asking, “Why doesn’t Tommy speak?” At age 8, he was diagnosed with dyslexia, first by a social worker, and later through testing in the schools. He had consistent difficulty through high school with reading, writing, and spelling that resulted in low grades. He noted contentious relationships with teachers who misunderstood his difficulties with learning. He drew a sense of self-esteem from success in part-time jobs, athletics, and art. He went to college due to his mother’s insistence but was quite reluctant and had an intense fear of failure. He found a niche in industrial design and was eventually ranked number one in his prominent university program. He feels that his pattern of overachieving in adulthood is related to a sense of insecurity from his experiences with dyslexia.

Jeanine is a 25-year-old, single European American woman. In early childhood, she noted that others were concerned about her ability to concentrate. She remembers them telling her that her mind used to “float.” She was diagnosed with learning disabilities, primarily in the area of reading, through formal psychological and educational testing in the sixth grade. She had difficulties related to reading, writing, and attention throughout grade school and high school. She felt very stigmatized in grade school due to the testing process, her difficulties with learning in the classroom, and having to be tutored. Other children consistently teased her. High school felt better, as she pursued a social niche that involved parties and rebellion; however, by that time, she had divested from academics. She participated in lower level classes and had the support of a resource teacher who consistently reminded her of her competence. In junior college, she pursued training in the field of education and was surprised and delighted by her academic success. She completed an associate’s degree. Currently, she has a viable career as a supervisor in customer service and is known for her strong work ethic. As an adult, she questions her sense of intelligence and wonders if she could have achieved more academically.

Steven is a 30-year-old, single European American man. He was diagnosed with reading problems in the third grade, and later with dyslexia in the seventh grade, through formal psychological and educational testing. He also noted difficulties with reading people and heavy reliance on sports to connect with other children. For 1 year, he attended a high school for individuals with dyslexia. He felt that the school was helpful, but he left because it did not have a sports program, which caused him to feel isolated. He also left to prove to others and to himself that he could function in the mainstream school system. In college, he majored in business on the advice of others. He eventually returned to graduate school to pursue his true interest, in history, and he completed master’s-level training. He used many accommodations and put forth exhaustive efforts to complete the degree. He currently teaches and works as a college-level coach. He feels that with persistence and support, he has been able to accomplish important academic goals. Steven lives on the West Coast and was interviewed by phone. An exception was made to a face-to-face interview because of his unique experience in attending a school for dyslexia.

Jerome is a 42-year-old, single European American man who lives in a bilingual city in Canada. In early childhood, others noted that his language and speech were delayed. He failed first grade. He was diagnosed with learning disabilities through psychological and educational testing, at first in the third grade and later in the sixth grade. As an adult, he was tested again and diagnosed specifically with dyslexia and attention-deficit disorder. He had significant difficulty throughout his school experience, primarily with reading, writing, and spelling. He persisted with tutoring and academic support from his religious community and
put forth exhaustive efforts. He reported that his teachers’ misunderstanding of his academic difficulties resulted in contentious relationships that further motivated him to prove himself. He persisted and graduated from college with a degree in social work but had problems becoming licensed due to the bilingual language requirements of his country. (Dyslexia interfered with his ability to master a second language.) He eventually was licensed, but he is unable to work in his field due to a lack of required accommodations. He remains in that province to care for his elderly mother and currently works as a nursing assistant. He is disappointed that he is underemployed and feels a sense of insecurity in his career. However, he draws a sense of strength from his accomplishments and is attempting to pursue parts of life that he had missed out on, such as dating, due to all that went into coping with his disability. Jerome was interviewed by phone. An exception was made to a face-to-face interview because of his unique experience as a citizen from another country.

Bob is a 35-year-old, married European American man who has a son with dyslexia. He noted that his early childhood development was relatively typical, except that others commented that he would lift himself to crawl in an unusual manner. His son, who also has learning disabilities, exhibited the same symptom. Teachers in the first grade diagnosed Bob with reading problems. He received extensive psychological and educational testing in the fourth grade and was diagnosed with dyslexia. He stated that the testing process felt alien and that no one ever adequately explained his learning disability, leaving him alone to interpret his difficulties in a highly negative manner. After his diagnosis, he felt that he was promoted without completing the requirements of the various grades, and he worried about his future. He failed to receive the assistance he needed to adapt, although he did note a small number of supportive teachers and tutors who at least helped him to feel better about himself and, at times, enabled him to learn. He had extensive difficulties in the classroom and was consistently teased by other children, particularly when he read aloud. He drew some self-esteem from his athletic and artistic abilities. He learned to read after he graduated from high school. He found a niche in adulthood and is a highly successful trader. He also has invented a well-known software, which is in common use on the Internet. He has been instrumental in assisting his son who has learning disabilities, securing assistance from national experts. He takes pride in his accomplishments, but he also notes unresolved feelings of anger due to his experiences with dyslexia as a child. As a consequence, he continues to feel insecure with his peers. He notes that he addresses these feelings through overachievement and by distancing himself from others.

Bill is a 45-year-old, married European American man whose son was also diagnosed with learning disabilities. In the second grade, his teacher diagnosed him with reading problems. He received tutoring throughout grade school. He experienced difficulties in reading, writing, and spelling throughout school. He felt alone with his learning difficulties and labeled himself as “lazy” and “stupid.” Sometimes, his teachers also labeled him in this negative manner. He went to a high school that emphasized class participation, which helped him to adapt. He also excelled in athletics. He attended a number of community colleges as he began his working life, eventually completing a 4-year degree in his mid-twenties. He discovered visual–spatial gifts that served to advance his career. He owns and operates a multi-million-dollar business, which performs upper scale renovations to buildings and homes. He, too, notes a pattern of overachieving that stems from insecurities related to his experiences with dyslexia. Under stress, he continues to label himself as “stupid.”

Deb is a 28-year-old, single European American woman. She experienced difficulties learning to speak in early childhood, which resulted in self-consciousness. Teachers in preschool diagnosed her with symptoms of dyslexia. Throughout grade school and high school, her parents, who were highly educated and well aware of her learning difficulties, provided a great deal of support within the home, so that she could proceed through the school system mostly unidentified. She devised a number of ways to hide her learning difficulties from her teachers and her peers that involved hard work, persistence, and support from her parents. Her athletic, artistic, and social abilities appeared to reinforce her sense of self-esteem.

Due to her self-consciousness, Deb refused testing until college, when she experienced academic problems that threatened her successful completion of the program at the highly competitive school that most of her family had attended. At that time, she was diagnosed with auditory and visual dyslexia. She received accommodations in the latter part of college, but only after extensive self-advocacy in an atmosphere that was skeptical about her learning disability. She persisted with the assistance of a very supportive boyfriend who helped to reduce her sense of stigma. She also joined and eventually chaired the Orton Dyslexia Society support group on her campus. In graduate school, she accepted accommodations, which were more readily available, and had a much more workable experience. She is a practicing psychotherapist and feels that she has attained her academic goals. She continues to struggle with her learning difficulties only when she has a higher workload and is under pressure. She feels that her experiences with dyslexia have made her more sensitive to the emotional experiences of others.

Fred is a 28-year-old, married biracial (African American and European American) man. He has a son with learning disabilities. Fred was diagnosed with learning disabilities in the area of reading in the sixth grade through formal testing, which he found to be quite helpful. Although he felt highly stigmatized by seeking spe-
ocial assistance, such as tutoring and resource class, he accepted it as it helped him to compensate. His parents provided a great deal of structure, which at times led to tension and conflict within the home. He worked and persisted, eventually doing honors-level work in high school, where he also took advanced placement college-level courses. After becoming hurt and angry when he was passed over for the National Honor Society for not having school-based extracurriculars, he elected to go into the military rather than to college. After his discharge, he found a viable niche in the area of real estate and was quite successful. For a variety of complicated reasons, he is unable to work in that field at this time and is instead doing minimum-wage stock work. He is currently experiencing career difficulty related to not having a college degree and being unable to work within his niche.

Trish is a 37-year-old, married European American woman who is the mother of a toddler. During her own early childhood, Trish noted, she consistently crawled backwards. She was diagnosed with reading difficulties in the second grade through observation and informal testing. She was placed in tutoring and special reading groups. She was tested again in high school and diagnosed specifically with dyslexia. She graduated from a state college with a support program for persons with learning disabilities. Her parents provided extensive tutorial assistance and also connected her with tutors outside of the home. Participation in tutoring and the extra time required to complete work meant significant sacrifice for Trish in terms of her ability to participate in extracurricular activities and to spend free time with peers. By high school, she gravitated toward a social niche in her personal life and to a certain extent divested from academics. She works as a flight attendant on a part-time basis. At times, she feels underchallenged in her work life and questions whether she could have accomplished more in school and in her career.

Joanne is a 31-year-old European American woman who is a single parent. Her mother, a nurse, first diagnosed her in preschool, noting stark contrasts between her ability and her older sister’s ability to learn the alphabet and read. When Joanne began grade school, teachers labeled her as “lazy” and “failing to try.” Her mother advocated for testing, assistance, and support during grade school. Testing occurred within the school system and confirmed the diagnosis. Her parents provided tutoring within the home and she also received tutoring in school. Joanne refused additional testing and support in junior high school and again in college, where she achieved average grades. In high school, she felt that she was “cured.” She declined help until her senior year, when she almost experienced failure in an accounting class. She went to college for 3 years but left, reportedly due to financial concerns. She enjoyed the related social experiences. She works as a bookkeeper in the accounting field, pursuing a former area of difficulty that she eventually mastered. She has returned to college as an adult to pursue additional training in her field and has achieved higher grades than before. She attributes her success to a more focused niche with real-life applications. She feels that her struggles with dyslexia have resulted in increased creativity, enabling her to “think outside of the box.” She is very independent minded.

Mark is a 30-year-old, single European American man. In early childhood, he had difficulties learning spoken language. He was diagnosed in the primary grades with dyslexia through comprehensive, formal testing. His symptoms were reportedly quite severe and involved extensive problems with reading, writing, and spelling. He received support within the school system, including tutoring and speech therapy. He felt that the time required for the services and supports separated him from his peers and resulted in social difficulties. His parents were affluent and enabled him to attend boarding schools for persons with dyslexia in junior high school and again after college, leading to mixed experiences. In junior high school, separation from his family resulted in a sense of loneliness. He felt uncomfortable with other students, many of whom had histories of delinquent behavior. He left the school after a limited stay and returned home. High school was a better experience. He continued to work very hard and had special assistance, but he also found a niche in a part-time job where he met a number of friends and began to date. He went to a pre-college program for persons with dyslexia after high school to work on study skills for a couple of years. He recently graduated with a degree in business from a college with a support program for persons with learning disabilities. He had very positive experiences in these two settings. Due to problems with organization and reading and writing, he was fired from his first job after college, which was a position as an administrative assistant. He had difficulty securing his current position in personnel placement and management, which appears to be a better match. He persists with the support of a girlfriend who is very understanding. He worries that dyslexia will continue to interfere with his ability to maintain his career.

Roger is a 31-year-old European American man. His father and all of his brothers have dyslexia. He had difficulties with spoken language as a child. He was tested in the primary grades. Placed in special education classes, he did not learn and felt like a “failure.” After an unsuccessful legal battle with the school system, his parents, who had the financial means, sent him in the seventh grade to a boarding school for persons with dyslexia, where his academic performance dramatically improved. He was accepted into a unique program for 2 years in junior and early high school, where he studied on a ship as he sailed around the world. He is a firm believer in hands-on and visual learning. He felt that a picture was “worth a million
words" as he studied the arts and sciences and was simultaneously able to visit corresponding historical sites in a number of countries. He remained with the first school for dyslexia until mid-high school. He graduated from a similar high school that was accredited. He went comprehensively to a highly competitive college, majoring in history. With hard work and a great deal of self-imposed structure, he graduated with honors. He currently manages an upper scale antique business and is quite successful. His career draws on his academic background, talents in art, and experiences with travel.

The Collective Story and Ways of Life

The collective emotional story of participants involved shared experiences and dilemmas over the course of life. It will be presented in the remainder of this section and supported by quotes from the participants' accounts. The study contains more quotes and findings than can be included in this article due to limitations of space. The stories were analyzed using the structural framework provided by Atkinson (1998). The elements of the story examined and used to illustrate participants' experiences are drawn from Aristotle's Poetics, which have been adapted for the field of narrative analysis by Prince (1987). They include prologue, exposition, plot, subplot, resolution, and epilogue, and they will be defined as the findings are presented.

Prologue: Possible Differences and Difficulties in Early Childhood. The prologue is "the initial section of a narrative" (Prince, 1987, p. 78). It occurs before the set of circumstances that the main characters must confront. Many parents and professionals assume that the difficulties related to dyslexia and other learning disabilities begin in school, when the child's academic problems first become apparent. A possible prologue to the story was an awareness of differences or difficulties in the areas of spoken language, attention, or coordination during early childhood. Feedback from others, such as parents or other family members who noticed them, left those who had such experiences at a very young age with the emotional concern that "something's different about me" or "something's wrong with me." Mark, who works in personnel placement, describes his experience as follows:

At a young age, I started to notice, my family and doctors started to notice that I had a hard time speaking and, at one time, probably up to 5 years old, I could not speak very well at all.

Deb, a psychotherapist, on her early childhood problems with spoken language:

Well, I used to get really frustrated, like people weren't listening, people didn't ... There's something wrong with me that people don't understand me, and it became such an effort to describe anything, that I didn't do it as much after that. I mean, the more I struggled, the more I'm "Forget it. It's not worth it."

Not everyone who interviewed for the study or reviewed the results reported or related to this experience. Consequently, it is considered a possible part of the story.

Exposition: Failures, Misunderstandings, and Trauma at Early to Middle School Age. The exposition is the set of circumstances at the beginning of the story (Prince, 1987). By early to middle school, each participant encountered unexplained difficulties and failures that called into question their sense of intelligence and motivation. Others often misunderstood their problems. These experiences resulted in the child feeling as if "something's wrong with me." This situation was the exposition in their stories. Jerome, a nursing assistant, describes his experience during the primary grades:

Once I started to hit school, that's where they noticed that there were real problems. We're talking about the early 60s, so most of the problems would have been associated with, "Oh well, it's emotional, or there's something in the family that's wrong." I was promoted on trial from kindergarten and then I failed Grade 1. Grade 1 was really horrible for me because I daydreamed, I was always in the corner; I wasn't hyperactive, and I don't think the teachers in school could figure out what was wrong with me until Grade 3.

Under certain circumstances, participants noted that the exposition could feel "traumatic" or like a "nightmare." At this stage, public experiences of failure—primarily in the classroom—coupled with gross misunderstandings and negative feedback that felt harsh could result in intense feelings of shame and humiliation. These episodes called into question fundamental qualities of the individual, such as intelligence, emotional state, and work ethic. In such cases, participants most commonly felt that others thought they were "lazy" or "stupid," leaving them with disturbing questions and self-doubts.

During grade school, reading aloud was the most common example of "trauma" noted by participants. Those who successfully avoided such episodes feared their possibility. The potential for this type of experience usually began during early school age, but it could be repeated at various points throughout the participants' lives. Bob, a commodities trader, describes his experience in Sunday school:

That was another place where everybody had to read, you know, passages out of the Bible. This teacher I had, I had the same teacher from first grade all the way through eighth grade. This guy knew I couldn't read and every freaking week he'd make me try to read. I don't know if you've experienced this, but you don't know how humiliating this is, to try to read something you... you can't read. It's a paragraph this big and it takes you 10 minutes, with him "helping out" to read the thing. It would take 10 minutes...
to read the paragraph. And the kids were all chuckling and laughing. I would get hot. And I remember my cheeks would be burning on fire. And I’d get to a point where I couldn’t even concentrate. I couldn’t read anymore. It was so humiliating, so degrading to me.

Complication in Early and Middle School Age: Testing and Diagnosis. The complication, or complicating action, is “the bridge between the initial situation and its final modification” (Prince, 1987, p. 15). It is what happens in the story in response to the initial set of circumstances. Testing and diagnosis were the first of two complications in the life stories of the individuals who were interviewed. These processes were experienced on a continuum between further trauma and affirmation. Individuals generally reported an experience between these two poles.

The idea of being tested or assessed felt traumatic, as it in some way confirmed the fear that “something’s wrong with me.” Accurate and relevant findings that adequately explained the difficulties, coupled with positive explanations that emphasized strengths and resulted in adaptation, led to affirming experiences that reduced the sense that “something’s wrong with me.” Testing that failed to yield useful information, or that was not explained in a positive manner, led to further trauma. The experience of testing and diagnosis appeared to set the stage for children to develop negative or positive patterns of compensation throughout the rest of their childhood and adolescence. It profoundly influenced the course of their lives. Fred, a real-estate broker, describes his affirming experience:

I remember my mom saying she wanted to have me tested, and while I got to miss school to be tested, I really remember not wanting to go because I felt like they were going to tell me that I’m stupid, and I was going to cry, and you know, I’m no good at anything, and I just can’t do this homework any more. I remember that was kind of traumatic. But I took the test, and the test didn’t seem real difficult. I mean, it wasn’t inkblot and tell me about your mother type stuff, but it was a lot of read some paragraphs and then answer these questions, and here’s some shapes and different things. So I thought it was actually kind of cool, and it lasted all day, and that was kind of an interesting thing. From that point, I started getting a little extra help, and I started seeing a tutor after school.

Jeanine, a customer service manager, had a more traumatic experience of the testing:

Being so young, I felt as if it was my fault or something. They did all these tests on me, weird tests, because they were trying to pinpoint what my learning disability was and I just, you know, it was scary, and I think my Mom could have been more helpful. I think she or my Dad could have been like, “Nothing is wrong with you,” instead of being, “Oh, they want to do these tests, you need to go to a doctor.”

It [the testing report] said how I had all this… said I was depressed, I was nervous, that I had anger toward men and I felt women were aggressive or something, I don’t even know. But I was 11 years old! They thought I was out to hurt somebody, older women or something, and that I thought men were hard to make happy or something.

Plot and Subplots: Contending with the Learning Difficulties and the Sense that “Something’s Wrong with Me.” The plot is the predominant theme in the story, which is responsible for its emotional effect (Prince, 1987). The central plot of the collective story became the child’s contending with the functional aspects of learning difference, the emotional sense that “something’s wrong with me,” and the related negative impact on self-esteem. Participants’ lives were a combination of subplots involving the interactive fit between their areas of competence (including talents and gifts) and educational resources, and the emotional support within their environments. Subplots are supporting themes that specify how the central plot unfolds (Prince, 1987). Most subplots involved a benefit and a cost.

The affirming subplot. The affirming subplot included experiences with activities and with others who facilitated adaptation in areas of difficulty and increased self-esteem. Deb, a psychotherapist, describes her positive experiences with a teacher who provided special assistance with writing and test taking:

I think it reinforced what part of me already knew, “That it’s okay, I’m not lazy, I have a disability that I was born with, that doesn’t necessarily have to mean that there is something wrong with you. That it can be an asset. That you can conceptualize things differently. That you’re acceptable the way you are. That you’re not lazy; you’re smart, you have something to contribute.” That’s the way she always treated me.

Affirming experiences generally came with the cost of sacrifice and commitment and involved perseverance and frustration tolerance. Mark discusses the social sacrifices he had to make in order to complete his homework:

I was pretty immature (with other kids) because, you know, I missed out on things because I was always home doing homework, or I’d go play sports, but I didn’t have time to go out with people. I had to go home and do homework.

The adversarial subplot. The adversarial subplot involved chronic experiences with others who misunderstood and consequently attacked the individual’s sense of intelligence and motivation. Tommy, an industrial designer, describes his experiences with a teacher who misunderstood his problems:

I barely got out of high school. My traditional grammar class, I put off until my senior year, last semester. And Mr. Shaw shoved it up my ass. I mean, he let me out on a D-, and that was just to get me out of school. But he made a big point about me being not dumb, but not capable in this class in high school.
Experiences with perceived adversities sometimes served to motivate children and adolescents to work hard to prove them wrong. In such instances, they developed "I'll show you" responses, which gave them traction to persevere with their difficulties. However, this benefit came at the cost of the individuals' being left with the burden of very serious concerns about the nature of their intelligence and work ethic. It also encouraged denial and independent action that could separate them from useful resources.

Steven, a college-level coach, discusses his experiences:

They [the staff at the high school he attended for persons with dyslexia] made the mistake of telling me that I couldn't make it in the mainstream school after a year in their program. So that gave me the gumption to go and prove everybody wrong. The truth was, I would have been probably better served to stay there another year, not that my grades were a problem, but it took more effort than probably it needed to take for me to achieve the kinds of grades I wanted to get.

The alternative subplot. The alternative subplot included experiences with activities and with others in areas that were unaffected by the learning disability and maintained self-esteem. Bill, a contractor, notes why sporting activities were so important to him as a child:

But in swimming, I excelled. I excelled in swimming. So then, all of a sudden, I was getting positive feedback, and it was very helpful to me as a kid growing up. The strokes and the feedback I got.

Alternative experiences could enhance or detract from efforts to contend with the difficult aspects of school. Tommy, a top industrial designer, discussed how his experience of work in high school improved his sense of self-esteem. He discusses how he almost used these experiences to avoid college:

I worked in the maintenance department, I worked in the kitchen, and I saw a life in the culinary arts. You know, got hooked up with the chef, the executive chef, and he said, "Well, we have this wonderful training program. We'll send you around the world and you could be a chef and do whatever you want." And I was seriously going in that direction until my mother made me quit. She said, "You know you are getting close to college so you're going to go to college; you're going to try it for a year. If you don't like it, you can do whatever you want. But you are at least going to go."

The absence subplot. The absence subplot involved the lack of others who understood or accepted the nature of the learning struggles, which resulted in loneliness, isolation, and further shame for the child. Trish, a flight attendant, discussed her sense, at times, of being alone:

I think I slipped through the cracks, is what I think. I was a very passive little girl. I wasn't the class clown; I didn't do anything. I did my homework. I mean, I remember being frustrated and crying in class because I couldn't get it. And I do believe that I was just passed from grade to grade to grade.

Unfortunately, on this subplot, there was no benefit—just the experience of loneliness and shame. Bill, a contractor, describes being alone with his struggles, which caused him to conclude that others who said he was lazy or less intelligent were correct:

It's just that you go through this thing alone as a kid. You're alone with it, and it's obviously very emotional; it's affecting me today. It's a fight you fight by yourself, and there is no other way to put it because nobody outside of you, and including you, understand it, so they must be right.

Complication: Finding a Niche in Adolescence and Young Adulthood. Finding a viable niche in adolescence and young adulthood became a second complication in the participants' lives. Having a niche at this stage on which to build an academic program or a career improved adaptation and self-esteem and could dramatically change a person's life. Failure to find a niche made for continued struggles. Bob, a trader, discusses his experience of finding a niche after high school:

I don't know why I got into it. I don't know exactly how I developed in my mind, the way I taught myself to be able to compute numbers. But I will say this: I somehow, some way, taught myself a way to figure out all the computing I have to do without using a calculator. And doing it just as fast if not better than everybody else that's down there. And I compete against Harvard, Yale, and MIT grads. You've got to remember you're talking to a guy who barely graduated high school, and I could barely add and subtract. Here I am, I'm setting theoretical values on 130-day options that are based off the 30-year government bond. That's what is truly mind-boggling to me, I don't work for anybody. I work for myself.

Roger discussed difficulties with his first position after college in the hotel industry:

I did a management training position. I was a bartender, I was a receptionist, and I worked at the front desk. Receptionist—you know, answer the telephone and things like that. I found it a very mundane, tedious job. Absolutely boring, and I think a whole lot of language problems came out in doing that. I mean, I felt it was very hard. You know, if someone was a foreigner, their English wasn't that great, I had no idea how to decipher what they were saying. I just ran into a lot of problems with that.

Resolutions and Four Adulthood Ways of Life. The resolution is "the part of the story which goes from the beginning of the change in fortune to the end" (Prince, 1987, p. 81). Through the complications, the set of circumstances at the beginning of the story becomes resolved. Resolutions of stories involved four adulthood ways of life (Ruth & Oberg, 1996). A way of life for persons in this study was composed of...
a predominant pattern of functional compensation in adulthood. The four ways of life were tentative compensation, alternative compensation, gifted overcompensation, and compensation. Each resolution has a corresponding set of emotional concerns.

**Tentative compensation.** Tentative compensation refers to continued difficulties with completing tasks affected by the learning disability. Persons who exhibited this pattern had problems functioning in their jobs or their personal lives that were similar to the ones they had in school. Such failures continued to negatively affect their self-esteem and resulted in a sense of insecurity well into adulthood.

After taking a number of years to complete college due to his learning difficulties, Mark held two positions that he eventually left because of his problems with assigned tasks that were negatively affected by his learning disabilities. He currently works in the field of personnel, placing temporary employees, a position from which he reports that he derives minimal satisfaction. He worries about his ability to succeed and to maintain his current and future positions:

> Because of my ability, I have found something where I'm making decent money. I'm not doing writing. I'm very fortunate. Negative because I need to do writing, because there are too many jobs out there that require writing skills. Basically, my job is all communication, oral communication. Names are a bear, but basically my proposals are done for me. My boss has them in the computer, so there's nothing I touch. It's phenomenal for me. It's the best I can ever ask for.

The problem I have still in my life is I'm always going to wonder if I'm going to succeed in life; I think I'll always have that in my life. I'm serious. I have a great place now. I just bought a place. And I always say to my father, "Am I going to be able to keep this?" You know, I'm worried. I think that's always going... especially after my first two jobs, I'm always going to worry in the back of my mind, "Am I going to be fired?" I mean, I deal with... I think what scares me in life is the unknown—I'm in a job I really like, I'm not the best at it, but I'm getting better at it, and my concern is, what happens after this job? I'm always going to have that feeling.

**Alternative compensation.** Alternative compensation involves the pursuit of a niche in an area unaffected by the learning difference. Individuals who exhibited this pattern felt secure in their areas of expertise, but less so about their general sense of intelligence, due to their histories of learning difficulties in school. They felt under-challenged in their work lives.

Jeanine works in customer service—a career built on a social niche that began in high school. She discusses her regrets and self-consciousness about her academic past with dyslexia:

> I wish if I could do it over again, and I would do it differently. I wish I had focused more on school. I wish I had finished college. I still might. It's embarrassing for me to say that I didn't finish college, because a lot of people I work with have degrees, and there are not a lot of people who don't have degrees.

> In school, I just think that it was easier to accept myself as a social and fun person, where now I need to accept myself as a hard worker. I think, back then, I think I really just chickened out. I didn't like the challenge as much as I now like the challenge.

**Compensation.** Compensation involves gradual success with adaptation in areas of difficulty in school and work over the course of life. Individuals who exhibit this pattern successfully compensated in school and attained academic credentials more closely in accord with their intelligence than the others in the study. Success along these lines enabled them to feel a stronger, more positive sense of work ethic and intelligence. However, such persons still reported self-esteem issues related to the long-term experience of contending with a learning disability.

Steve, a college-level coach who initially studied business, returned to school to complete a master's degree in history. He discusses his sustained efforts to actualize his gifts in areas of interests affected by his learning disability. He notes how his eventual success quieted concerns about his intelligence and led to a sense of mastery over his dyslexia:

> If I were an easier reader, I would have been in history or philosophy very easily or very quickly out of high school. And all of that is sort of because I have the label. I had something to point to called dyslexia, and I was able to say that this mandates that I should stay in business or communications. And that's a lot more subtle than saying, "Well, I believed them when they said I was stupid." I ended up at the same place, it just took me a few extra years. But I'm doing what
I want. I’m in history, I’m coaching football, and dyslexia can’t affect that.

**Epilogue: Integrating the Emotional Experience in Adult Life.** Finally, participants’ lives in adulthood were characterized by an epilogue that involved individualized attempts to integrate the emotional experiences related to their histories of living with dyslexia. An epilogue is “a final section in some narratives. The epilogue helps to realize the full design of the work’” (Prince, 1987, p. 26).

Participants generally reported that their experiences had left them with an added sense of emotional insecurity. This sense involved feelings of heightened self-consciousness or low self-esteem, particularly in reference to work or career. It could also extend to interpersonal relationships or other significant areas of one’s life. The fact that participants had these feelings at times surprised others who knew them, such as peers, family, or friends (particularly those who did not know or understand their histories of living with dyslexia). Such feelings can be inconsistent with how competent these individuals otherwise appear in adult life. Bill, a contractor, notes that even though he has achieved exceptional financial success and recognition in his career, he continues to feel insecure. He describes his lingering feelings of insecurity:

> For me, it has lessened the last … I just turned 45, and it’s just now, within the last two years, starting to lessen for me. That insecurity isn’t as strong as it was, but it’s still there. I don’t know if it will ever go away for me.

All participants reported ways in which they were attempting to attend to self-esteem and loss issues related to their experiences as children and adolescents. Such attempts were not uniform or systematic; however, all individuals who reviewed the collective story related to and affirmed each of the following ways of attending to emotional concerns described by their peers. If they had not personally employed one of these methods, they could understand why someone else who shared their experiences would.

**Discussing the experience with others who understand could be cathartic and improve self-esteem through serving to counterbalance past experiences of misunderstanding and trauma.** Bill discusses his friend Terry, who relates to his history:

> And my buddy, Terry, he doesn’t have it, but his wife has it, and his kids have it. Two of his kids have it. You know, they talk to my wife. Terry’s talked to me. I hold Terry in high regard because he is a guy who is smart, he knows a lot, he’s good in business, and he doesn’t have this problem. So it’s interesting to talk to him. He can relate to it. He doesn’t sit there when I say something and go, “You always go back to this childhood. Oh, you’re stupid.” He would never say that. He’s a friend, and friends wouldn’t do that to friends.

**Situating struggles in the context of achievements appeared to help participants avoid bitterness and improve self-esteem.** Jerome, a nursing assistant, has a degree in social work but is unable to work in that field because of his continued learning difficulties:

> There are people who really are angry about the fact of what’s happened to them. I try not to be in that category because you can really wind up letting this eat you up inside. You deal with problems of self-esteem and aggravation. I’m functioning. I’ve got a job. I’ve managed to join the corporation of social workers, although I am not practicing. My life could have been a lot worse.

**Viewing their learning difficulties as learning differences, which result in unique strengths and an appreciation for diversity, fosters adaptation and self-esteem.** Joanne, a bookkeeper, discusses the advantages to “thinking outside of the box”:

> In my work, you have to kind of be able to get into the mind of the person who put that down on paper and think of where they may have put it, so I guess I have more advantages than they [other accountants] do, all my life always having to try to think outside the box. At this point, I take it as an advantage, not as a hindrance or problem.

I don’t put people in categories, I don’t label, because I’m used to thinking differently. I’m used to doing things sometimes differently than other people do. If somebody does something differently, it doesn’t appear to be different to me. So I don’t have specific things I expect of people. I don’t expect everybody to go in one direction or do things like that. If they want to walk backwards, fine with me.

Deb, a psychotherapist, focused on some of the strengths she derived from the experience:

> Well, in some ways I think it gives me more empathy toward people. I know what it’s like to struggle in a certain way. I learn differently and think differently than other people do.

**Thoughts or fantasies involving confronting experienced adversities and paying homage to allies appear to affirm positive feelings and dispel negative feelings about the self that stem from misunderstandings and traumatic experiences in childhood.** Bob, a trader, discusses his fantasies about confronting peers who made fun of him. He talks about bringing people back to his home that is a symbol of his success as he anticipates his high school reunion:

> I enjoy running into kids I went to school with, and I drag them back here. Not to be a jerk or an asshole, but I can’t wait for my 20-year high school reunion. I really can’t. It’s as though I want to say, “You know what, I did better than you, you prick.” There are a couple of guys that used to really ride me hard, and I’d love to shove this right up their asses.

Bob also discusses his wish to find and thank a very supportive tutor who consistently reassured him that he would succeed in life:

> You know what. If I could find Mrs. Hanover [his former tutor, who told him he would be a success], I’d like to bring...
her some flowers and hug her and tell her how much I truly love her. I really would. I guess I never pursued it, and if I did really push hard for it, I could probably find her. You know, I might do that; I really might do it. I would really like to go find her and tell her, "Thank you." I know she’d probably really appreciate it.

Parenting a child with learning disabilities appeared to promote a revision of self-concept in a positive way in the service of helping one’s child adapt. The process of understanding and attending to the needs of their children who have learning disabilities was initially painful but ultimately helped participants to better understand themselves. Bill discusses the process of having his son diagnosed, which caused him to revisit how he felt about his learning disability and what it meant to him:

I guess the easiest analogy was I always felt I was on eggshells [prior to his son being diagnosed]. I was always waiting for the bottom to crumble, and it is a terribly uncomfortable situation to live with. When my wife was first trying to have my son diagnosed, there was this conflict that we were having, because I could see that Dave was struggling the way I did as a kid, and I said, "He’s a boy, he’s going to be fine." I said, "He’s no different than I am." And truthfully, he isn’t. There are many similarities. So although I was defending him, but also trying to make my wife see or justify to myself that if "I’m okay, he’s okay. Or if he’s okay, I’m okay." Because I struggled my whole life to be successful, and I was afraid that all of a sudden, well, somehow, some way, it was going to be taken away, because, again, this is all conditioning from childhood. It’s like "You’re lazy, you’re not trying hard enough, so you’re not going to be successful."

Now when my son was diagnosed—just to show you the difference—when he was diagnosed and he finished all his tests, on the ride home with him and my wife, my wife was asking him, "How do you feel, Dave?" And he said, "Well, I know I’m not stupid." And Dave is very gifted. He’s bright.

Participants who did not have children noted concerns for future generations that appeared also to be an expression of grief for their losses. Jerome expressed those feelings as follows:

I’m much more focused on the next generation of kids coming up, and I think we tend to think it’s going to get better, and I’m not sure it will. My message for the future is . . . based upon our experience . . . this is what it’s going to be for our kids. I don’t think I would say that kids will have an easier time of it in the future. I would hope they will, but I think, based upon what I’m hearing from people, unfortunately my story will be replicated by a lot of people.

The transition to midlife further eases related feelings of insecurity. As Jerome puts it,

As I get older, I’m sort of able to believe in myself a little more. Slowly but surely, after 40, I’m starting to look for people, and I’m starting to date, and I’m making less mistakes than I did. I think it’s also less of a hassle for me because, in a strange way, I’m not making this as important as it was. I’m not putting as much strain on myself that I have to perform in this area. If it happens, it happens. If it doesn’t, it doesn’t.

Implications

The implications of this study involve promoting functional and psychological compensation, reducing potential stigma and trauma, and bolstering self-esteem.

Early Childhood: The Case for Early Intervention

The symptoms or difficulties that are potential precursors of dyslexia or coexisting conditions can begin by early childhood (Pennington, 1991). In the early years, ages 0 to 5, children are at risk of these difficulties. Problems in completing developmental tasks expected of their peers, such as those involving language, attention, coordination, or others, will inevitably be noticed by adults, peers, and the child. This potential experience will affect the sense of self and self-esteem in a negative way, leaving the child with a very early sense that "something’s different about me" or "something’s wrong with me."

Having this experience during early childhood can understandably result in such an emotional sense becoming more deeply embedded in the personality or the sense of self of the child than previously considered. This phenomenon may explain, in part, the level and extent of the hypersensitivity to perceived criticism exhibited by some children diagnosed with learning disabilities, as reported by parents and professionals who attempt to assist them (Brooks, 1997).

Adults who have dyslexia are more likely to have children with the same learning disability (Rumsey, 1992) and, therefore, should be aware of potential signs of concern and ways to seek assistance. Early childhood specialists in various disciplines should be educated regarding these same signs and be prepared to intervene or to obtain assistance for the immediate difficulties. All involved would do well to foster an appreciation for differences in learning early on in the child’s life to facilitate attempts to adapt and to lessen the concern that “something’s wrong with me.”
Initial Difficulties in School: The Need for Supportive Attention

The symptoms related to dyslexia definitely become apparent by school age. Discovery of the learning disability was a process that inevitably involved time and the experience of difficulties or failures. Only after such a period was a diagnostic process usually initiated. In the interim, it is crucial for parents and professionals to develop an atmosphere of supportive responsiveness. Hopefully, all involved would view learning as a natural process and give children who struggle their attention and the benefit of the doubt. Such a philosophy is absolutely required to reduce the stigma associated with learning disabilities. Education for parents and professionals about the concept of a learning disability and the resulting learning differences would seemingly reduce misunderstandings that feel negative or traumatic through creating a more sensitive, supportive, and pluralistic culture of learning at home, on the playground, and in the classroom.

LD Trauma: The Need for Protection

In the words of participants, school-age misunderstandings can feel “traumatic.” In such instances, the participants’ experiences did not constitute a clinical diagnosis of trauma (American Psychiatric Association, 1994), as they had not encountered or witnessed a threat of death or physical harm. However, participants did repeatedly refer to these kinds of experiences as traumatic. Perhaps this phenomenon is in accord with what has been described as the trauma associated with having a learning disability (Orenstein, 2000). LD trauma for persons with dyslexia appears to involve gross misunderstandings of unexplained struggles with adversities related to hidden learning disabilities. Such misunderstandings publicly call into question fundamental qualities of the self, such as work ethic, emotional state, or intelligence, and lead to intense feelings of shame and humiliation on the part of the individual in question. Repeated episodes along these lines appear to result in heightened emotional insecurity and self-doubt.

Due to the intense feelings of shame, individuals in this situation appear likely to deny or even disavow their learning disabilities to protect their sense of self and self-esteem. Disavowal is a more extreme defense mechanism than denial, where something is seen but not conceived (Siegel, 1996). This finding is in accord with Palombo’s (2001) theoretical formulations concerning the self-narrative. The sense of self-consciousness observed by the researcher within the interview process may be indicative of participants’ lingering sense of shame and need to deny or disavow their traumatic experiences related to living with the learning disability.

LD trauma is reminiscent of the concept of cumulative trauma, as described by Khan (1974). Cumulative trauma involves “breaches in the mother’s role as a protective shield over the course of development from infancy to adolescence—that is to say, in all areas of experience where the child continues to need the mother...” (p. 55). For Khan (1974), the concept of mother equates to environmental responses and extends beyond the mother–child relationship to all of the child’s caregivers, such as father, teachers, and others who have the opportunity to support the development of a healthy ego or sense of self.

Caregivers failing to protect the child from gross misunderstandings characterized the nature of the LD trauma experienced by participants. Failure to intervene was often related to such others’ being unable to recognize or understand the learning disabilities involved and their emotional effects. The experiences of participants in this study indicate a strong need for caregivers who can help protect children from negative misunderstandings and LD trauma and who eventually enable them to protect themselves.

Protection along these lines would serve to lessen the sense of stigma and promote positive self-esteem, hopefully leading to a sense of acceptance that enables better functional compensation. Given that negative feelings from past experiences and some aspects of the difficulties in learning may continue into adulthood, understanding and protection can be pertinent lifelong issues.

The Need for High-Quality Testing and Sensitive Explanations

Identification through diagnosis or testing was a crucial part of the story. The need for useful and relevant information was critical to help participants to develop positive patterns of functional and emotional compensation. Equally important were explanations that helped the child to maintain a positive sense of self-esteem. Failure to attain such information and explanations felt traumatic and led to negative patterns of compensation. Access to high-quality testing and diagnosis appears essential. Sensitivity and care on the part of professionals and parents in terms of explaining the diagnosis in a positive manner, repeatedly over time, is indicated.

The Need for Attention to Functional and Psychological Compensation

The central plot of the story, contending with the learning difference and the sense that “something’s wrong with me,” leads to a number of implications. The importance of parents and professionals attending simultaneously to both the functional and the emotional issues is in accord with the findings of previous studies (Ambroz, 1990; Haufrecht & Berger, 1984; Migden, 1990; Rawson, 1977; Scott et al., 1992) and with Palombo’s (1985, 1987, 1991, 1993, 1994, 2001) theoretical conceptualizations. Diagnosed children may remain hypersensitive to perceived negative feedback and will always live with a hidden learning dis-
ability that is prone to being misunderstood. Advocacy and educational assistance on the part of parents and professionals will promote understanding and attention to the resulting learning difficulties throughout school and would ostensibly lead to positive compensation.

Attention to which subplots unfold in a child's life appears to be highly important for parents and teachers. A re-examination of the child's struggles, gifts, and resources may uncover talents, activities, or ways of adapting that enable the child to enter into subplots that improve adaptation and bolster self-esteem. Failure to attend to these issues may leave children compensating in a more negative manner than necessary. Due to the challenges and the hidden nature of learning disabilities, negative experiences and LD trauma are never totally avoidable. However, the emotional story uncovered by this study indicates that parental and professional support can reduce the frequency and intensity of these experiences.

The Importance of a Niche

As stated in other studies (Gerber & Reiff, 1991; Hellendoorn & Ruisjseenaars, 2000; Orenstein, 2000; Reiff et al., 1997) and in the work of Brooks (1997), finding the right niche has added importance in the lives of persons with learning disabilities. The participants in this study noted that niches enabled better compensation, with their learning difficulties and self-esteem issues enhancing the quality of their lives. Adolescence and young adulthood appeared to be particularly opportune time periods to re-examine difficulties, gifts, and potentially viable niches and careers. Parents, professionals, and those who are diagnosed should be mindful of and attentive to such opportunities.

The Continued Need for Support in Adult Life

The participants in this study, like those who participated in others (Gerber & Reiff, 1991; Hellendoorn & Ruisjseenaars, 2000; Orenstein, 2000; Reiff et al., 1997), were well aware of the struggles related to their learning disabilities in adult life. Similar to the Dutch study (Hellendoorn & Ruisjseenaars, 2000), which described its participants as "uncertain" (p. 235), the emotional story uncovered revealed that even under the best of circumstances, participants' self-esteem issues followed them into adulthood and resulted in an added sense of insecurity.

In adulthood, the participants appeared to have obvious patterns of functional compensation that involved various emotional and self-esteem issues. Patterns of functional compensation were in accord with the notion of "systems of accommodation" (Gerber & Reiff, 1991, p. xiv). In addition to the gifts and struggles of the person, related emotional concerns and self-esteem issues played prominent roles in the development of these patterns.

Individuals appeared reliant on their patterns to adapt and were inherently more vulnerable than their peers to changes in their lives that might affect these ways of coping. Moreover, they seemed to be integrating the emotional experience related to their lifelong struggles attempting to attend to self-esteem issues. Adulthood was ostensibly a time to revisit and hopefully improve patterns of compensation and feelings about the self resulting from the history of living with dyslexia. Parenting a child with a learning disability and midlife seemed to be prime opportunities to further such explorations. Professionals and significant others who understood their past experiences and the aspects of their learning difficulties that remained at play could potentially support personal growth along these lines.

Summary

The void in the literature concerning the emotional experiences related to living with diagnosed dyslexia led to a study of the life stories of adults diagnosed with dyslexia as children. The goal of the study was to uncover the emotional experiences resulting from living with the disorder over the course of life and to learn from the experiences of the participants. The life story method was used to examine the issues involved in an open-ended, exploratory fashion that enabled participants to spontaneously and authentically report their experiences. A collective story was uncovered and validated in an extensive member check process.

The story revealed that children may be aware of the precursors or associated symptoms of their learning disability by early childhood, and definitely by school age. They may feel different, or as if "something's wrong with me," earlier than is usually considered, which would affect their personality and emotional life, making for more pronounced difficulties with self-consciousness and self-esteem. The need for early identification and intervention to promote functional and psychological compensation was supported.

By school age, the experience of related difficulties can result in problems in school and in an emotional sense that others think that "something's wrong with me." Such an experience generally results in self-consciousness. It can feel traumatic during public experiences of failure, when the learning difference is misunderstood and the child has an intense emotional response, usually involving shame. A definition of LD trauma for persons with dyslexia was proposed based on these kinds of experiences and other, comparable ones that can extend throughout life. The need that such individuals have to be protected and to learn to protect themselves from such misunderstandings was highlighted. Depending on their quality and on how they were explained to the child, testing and diagnosis set the stage for negative or positive functional and emotional compensation. The necessity for high-quality testing and re-
peated explanations that emphasize strengths and coping was supported.

An awareness of how the child compensates, both functionally (with the learning disability) and emotionally (with the concern that "something's wrong with me"), was necessary to promote adaptation, a positive sense of self, and the realization of potential after the diagnosis and into high school. Subplots identified at this stage included experiences with activities and with others that involved affirmation, alternatives, adversaries, and absences. Each subplot was a pattern of functional and emotional compensation that involved costs and benefits (with the exception of the absence subplot, which had no apparent benefit). Individuals' lives generally showed some combination of these patterns. Niches in young adulthood could result in opportunities to dramatically improve functional and psychological compensation. Failure to find a niche led to continued problems along these lines. Attention on the part of parents and professionals to the process of discovering a niche is indicated.

The participants all exhibited patterns of functional and emotional compensation into adult life. The four ways of adult life identified included tentative compensation, alternative compensation, compensation, and gifted overachieving. The participants noted an added sense of insecurity they experienced as adults that was related to their lifelong struggles. In a variety of ways, they attempted to integrate the emotional experience related to living with the learning disability by tending to self-esteem and loss issues. Awareness and support from significant others and professionals is recommended to promote functional and psychological compensation in adulthood and to enhance personal growth and the quality of life for those who are diagnosed with dyslexia.

Limitations
Qualitative efforts cannot equate to or substitute for quantitative research. Hopefully, they can complement quantitative studies, resulting in more in-depth descriptions of the nuances involved and generating additional ideas for research. The findings and implications of this study pertain to what the experience of dyslexia feels like based on interviews with participants and reviewers and on any actions that those descriptions suggest, but they are not statistically valid.

Although the participants were asked to provide testing reports from their childhood, most no longer had them. Those who did appeared self-conscious about releasing such personal information to the researcher. Moreover, the ways in which persons were diagnosed varied among individuals in terms of the formal nature and comprehensiveness of the assessment and testing, depending on the availability of diagnostic resources within their school systems. Also, the stigma related to testing caused some participants to limit their pursuit of the diagnostic process. Unfortunately, this reality was reflective of the time period in which they were children. Many children today confront similar circumstances due to inadequate diagnostic resources and the stigma that continues to be associated with the disorder.

A decision was made by the researcher and his consultants to include participants who reported a diagnosis prior to age 14 without past testing reports, provided that the completion of the assessment tool previously described indicated a profile in accord with a diagnosis of dyslexia. It was held that inclusion in this manner would promote an accurate and relevant depiction of the emotional experiences of that group of persons who identified themselves as having had a childhood diagnosis of dyslexia or of a reading learning disability that met the criteria for dyslexia.

All persons who were interviewed came from at least middle class backgrounds. Two were of upper class status. By virtue of their socioeconomic positions, they probably had access to resources that less affluent persons may not have had. Consequently, their stories may represent more positive experiences than those of others with less financial means or poorer educational resources.

It was assumed that the persons who interviewed for the study were able to accept their diagnoses enough to admit and discuss them. Consequently, the stories uncovered may be reflective of the more positive experiences in the target population. Individuals who were in denial or unwilling to discuss their lives due to stigma may have been less likely to consent to an interview.

Only 12 persons were interviewed about their lives, limiting the number of perspectives contributing to the data pool. However, the length of the interview process was more extensive than in other forms of narrative analysis, and the high rate of review within the data pool and by others outside the pool lent credibility to the results. As the first persons formally diagnosed with dyslexia in our school systems are generally only 45 to 50 years of age, older adulthood cannot be described by these findings.

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AUTHOR'S NOTE
I would like to thank Bertram Cohler, PhD, Amy Elderidge, PhD, Constance Goldberg, MA, Donna Maloney, PhD, Joseph Palumbo, MA, and R. Dennis Shelby, PhD, for help I received in conjunction with this project. I would also like to thank Camille Hudeck, for transcribing the interviews, and the participants, for giving of their time and selves in the hope that others would benefit from their life stories.
NOTE

The researcher consulted with R. Dennis Shelby, PhD, chair of the research sequence of the Institute for Clinical Social Work, and expert in ethnography (Shelby, 1992, 1995), as he analyzed the texts of participants’ stories to ensure that all interpretations made were grounded in those texts. He did so also to control for any potential biases he held as a psychotherapist who works with people with learning disabilities and as an individual who was diagnosed with a reading disorder in childhood. Moreover, he consulted with Bertram Cohler, PhD, William Rainey Harper Professor, Committee on Human Development, University of Chicago, an expert in life story research (Cohler, 1982, 1987, 1993, 1996), to make certain that his application of the method was appropriate given the variety of ways in which it can be applied.

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