

THE EXPERIENCE OF HAVING DEVELOPMENTAL VISION IMPAIRMENT:  
A HEURISTIC INVESTIGATION

By

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A DISSERTATION

Submitted to

Center For Humanistic Studies

Graduate School

In Partial Fulfillment of the Requirements

For the Degree of

Doctor of Psychology

2006

Signature Page

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## ABSTRACT

This study explores the question, "What is the experience of having Developmental Vision Impairment (DVI)?" . Heuristic investigation was used because of the personal and complex nature of the phenomenon under investigation. A comprehensive literature review indicated that no similar studies had been done, but revealed some studies regarding the nature and prevalence of DVI, as well as the relationship between DVI and learning disabilities (LD). The researcher first immersed in the heuristic research techniques of self-dialogue, indwelling, and focusing. Data was collected from 13 co-researchers ages 17-70 who, during open-ended interviews, shared personal depictions of their experiences with DVI. Each interview was transcribed and reviewed for themes. The themes illuminated were: 1) Having no conscious awareness of having DVI, 2) Emotional and physical suffering, 3) Believing I am damaged (fundamentally flawed), 4) Struggling to adapt, 5) Re-examining my self-concept, and 6) Coming to terms with DVI. The central finding of this study is that the struggle of DVI is initially between the unconscious mind, which senses that something is wrong, and the conscious awareness that is unable to recognize having any visual impairment. Once diagnosed, the negative psychological impact of DVI can be reduced, and overall psycho-social functioning improves. The findings of this study have significant implications for the fields of psychology, optometry, and education.

## DEDICATION

I dedicate this dissertation to Marjorie Scott, Ph.D., Lee Bach, Ph.D., Sid Berkowitz, Ph.D., Ryan Blackstock, Psy.D., Betz King, Psy.D., Jeff Bernard, Psy.S., Aombaye Ramsey, Ph.D., Paul Paskiewicz, Ph.D., Clark Moustakas, Ph.D., My parents Norm and Judy, Sister Sasha, Brother Seth, Kristi Goldner and the Lloydster, my beloved grandparents, especially my Nana and Grampa, and my Zady Aaron, after whom I am named; to my nieces and nephew who inspire me with their love and enthusiasm, to Shawn, Jill, Nitza, Dave, Tom Hrzek and Kerry Moustakas, Ph.D., Jill and Nitza who supported me from the library, Kristy Tesnovich, and my whole crew of excellent friends: Uncle Mike, Jonny "Arvid" Hoff, Jeffro, Jimi-T (aka Jimbro), Marc Lahiri and Sharon, Vijay "Veege" Singh, Erich and Mark Dorn, Bradley R. "Shecky" Kahn, Brad Smith, Ellen Peck, Phaedre and Deidre Sassano, Rhon "the 'H' is silent" Porter, Jeremy from RISD; and the mentors who have seen me through, including Blair de St. Croix and Richard Masterson, Eric Fein, formerly of Marvel Comics; to the influential teachers such as Mrs. Boskey, Mrs. Bitker, Dr. Westhoff, "India" Scott at RISD, Constantine Eretescu, Mr. Arsenau, Ron Nasky and to the many fine people who have cheered me on along my journey.

Thank you for all over your help, support, encouragement, patience, time, alcohol and other forms of love. Perhaps I could have made it here without you, but the journey would be far less memorable and the reward would ring hollow without you all to share my triumph with in the end.

## ACKNOWLEDGEMENTS

Special acknowledgment goes to my entire committee, including Drs. Marjie Scott, Bruce Hillenberg, John Olesnavage, and Ryan Blackstock, as well as to Dr. Clark Moustakas, who along with Cereta Perry, and Diane Blau founded CHS, and to President Kerry Moustakas and the rest of the staff who now shepherd CHS as it evolves into the Michigan School of Professional Psychology. Further acknowledgment goes to Dr. Betz King, whose friendship and support over the years was a shining part of my doctoral experience. Also, I acknowledge the role of my classmates, who provided me with encouragement, support, feedback, and platonic, altruistic love over four wonderful, beautiful, meaningful years. Namaste`

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## Chapter I

## Meaning of the Research Question

Dr. William Reynolds covered the five-year-old's left eye while the boy read an eye chart. The boy's mother wondered aloud why an exam from an eye specialist was now required to enter Kentucky schools, especially because her son seemed to see fine. Then Reynolds covered the boy's other eye, and the youngster piped up, "Oh, that's the eye I don't see out of." Reynolds recalls the stunned mother almost falling out of her chair. (Optometric Extension Program [OEP], 2005)

This chapter introduces my topic of interest and includes personal, professional and historical information along with the social relevance of the topic. I state my research question, explicate the relevance of the topic to my field and degree, and give complete psychological definitions of the terms in the research question. I discuss the basis for my interest in learning more about the experience and impact of subtle, chronic Developmental Vision Impairment (DVI) on a person's identity, self-image and self-concept, accomplishments, and social and emotional development; in other words: his or her life.

*Autobiographical Connection to the Topic*

I was born with a Developmental Vision Impairment that has affected many facets of my life, both negatively and positively. The amazing thing is, until I was 29 years old, no one knew I had a vision impairment, not even me. I

wonder what I could have accomplished had I not faced an invisible hindrance to my academic and athletic success? What might have been different in my life if I had understood the limitation I faced and had the help of family and professionals? How might my self-image and self-concept developed differently if I had a logical explanation for the many difficulties I experienced? In other words, how might the course of my life been different if I had known at age 9 what I learned at age 29? My DVI may have brought me many challenges, but also has resulted in a number of unexpected strengths. As a direct result of facing challenges produced by having DVI, I have created adaptations that give me strength and confidence in my adult life, especially in the academic arena. I have used my fear of failure and overall academic frustration to fuel my efforts to obtain multiple higher education degrees. I have developed considerable academic and social skills as a direct result of my DVI.

#### *The Research Question*

People with Developmental Vision Impairment encounter more obstacles than simply impaired vision. Individuals with DVI face a myriad of academic, social and psychological challenges. In addition, struggling with DVI



may promote adaptations and have positive influences. Any truly effective solutions to the problems caused by Developmental Vision Impairment, or understanding of its potential positive aspects, will require an exploration of the individual's whole, subjective experience of having DVI. The way that I acquire this information is to ask the formal research question, "What is the experience of having Developmental Vision Impairment?"

I believe that this question is open ended enough to allow me to gain information about the various aspects of the phenomenon and its positive and negative effects on an individual. The resulting data could help to determine the kinds of assistance (e.g. psychotherapy, vision therapy) that can benefit DVI individuals. The answers to the research question may also provide direction for future qualitative and quantitative research.

#### *Definitions of Terms*

My research question is, "What is the experience of having Developmental Vision Impairment?" For this section, I define the terms *experience*, *having*, *vision & sight*, and *Developmental Vision Impairment (DVI)*.

*Experience.*

The word *experience* encapsulates and refers to the whole of a person's interaction with a phenomenon. The whole includes subjective emotion and feeling in addition to concrete thought, logic, and reason (Smith, 1996). The components of experience can include an individual's perception, awareness, ideas, thoughts, beliefs, assumptions, history of doing, activity, and process with regard to a given phenomenon.

The word *experience* was chosen for the research question to reflect and facilitate the philosophical orientation of this study: That each individual participant's whole, personal, and first-hand interaction with DVI is a valuable, and, in fact, necessary, source of information, to develop a full understanding of DVI. Put another way, the study is founded on the belief that DVI as a phenomenon cannot be fully understood without reports from individuals who have had and lived with it.

The word "experience" can be used as a noun, "An event that is lived through, or undergone, as opposed to one imagined or thought about (Corsini, 1999, p. 351);" as a verb concept: "Actual living through an event or events;...passing through and adjusting to a particular set

of circumstances;" and as an descriptive, adjective manner: "Experience is not static; it connotes activity; process, happening, doing;" and as a form of content, "...the totality of mental phenomena at a given moment as directly received, thus excluding inference (English, H.B. and English, A.C.,1958, 193-194)."

As it is used here, the word "experience" draws much of its definition from the work of humanistic psychologists. Specifically, it draws from the work of Carl Rogers who wrote about the role of experience in significant learning (Smith, 1996). Rogers described experiential learning as fundamentally different from learning derived through reading, hearing about, or other indirect experience with a phenomenon (Wikipedia, 2005). Experiential learning, therefore, has several defining qualities. According to Smith (1996):

1. It has a quality of personal involvement—the whole person in both feeling and cognitive aspects being in the learning event.
2. It is self-initiated. Even when the impetus or stimulus comes from the outside, the sense of discovery, of reaching out, of grasping and comprehending, comes from within.
3. It is pervasive. It makes a difference in the behavior, the attitudes, perhaps even the personality of the learner.

4. It is evaluated by the learner. She knows whether it is meeting her need, whether it leads toward what she wants to know, whether it illuminates the dark area of ignorance she is experiencing. The locus of evaluation, we might say, resides definitely in the learner.
5. Its essence is meaning. When such learning takes place, the element of meaning to the learner is built into the whole experience.

The idea represented above is that the person who has an experience is affected by that experience. He or she is engaged with the experience in an authentic manner and, as a result will have a different relationship to and understanding of the experience than someone who has only read or heard about the experience second hand (Smith, 1996). This study seeks the unique, qualitative description of a person's experience with DVI in order to gain potentially valuable information that cannot be acquired through quantitative research alone. The word "experience" is used in this research question to stimulate the gathering of the unique and subjective substance participants have derived through personal encounters with DVI. The inclusion of such understanding facilitates the possibility of developing a whole and complete body of knowledge on the subject of having DVI.

*Vision and sight.*

*Vision* and *sight* are the two most basic and significant terms associated with DVI. While these two words may be synonymous in common usage, they are distinctly different when used in the field of optometry.

Wheeler & McQuarrie (1992) defined *sight* as the response of the eye to light. Sight is essentially the ability to see clearly. It is expressed by the fraction 20/20, which means that the subject can see from 20 feet a letter that a normal eye can see viewed from 20 feet. Twenty-forty (20/40) sight, for example, means that the subject can see from 20 feet a larger letter that the normal eye can see from 40 feet.

Vision is the ability to gain meaning from what is seen. It is the ability to see for information and performance. It is used for discrimination, integration, decision making, feedback, action, modification and adjustment...vision is the process by which we interpret and respond to our world. Working together, the eyes and brain create the world of vision. (Wheeler & McQuarrie, 1992, p. 3)

Another way of interpreting the relationship between sight and vision is that sight describes the mechanical function of the eye where as vision refers to the neurological interpretation and incorporation of sight, knowledge and perception. According to Cohen (1988):

Vision is not simply the ability to read a certain size letter at a distance of 20 feet. Vision is a complex and adaptable information gathering and processing system which collects, groups, analyzes, accumulates, equates, and remembers information. (p. 101)

Vision refers to the integration of stimuli, including thought, feeling, and sight, to derive understanding.

Understanding is, essentially, integrated material from numerous parts of the brain. Impaired vision is impaired perception of the world, and therefore impaired ability to act upon and interact with the world (Kaplan, 2002).

While a healthy person is born with the capability to see and visually perceive, vision and the skills that compose it are developed.

At birth, the eye is not fully developed. The infant needs stimulation with colors, shapes, and movement in the line of vision as the visual pathways complete their development and the brain learns to assimilate and interpret the visual images. By three months of age, random eye movement has disappeared, and by four months the infant can see near objects as well as those further away. By six months both eyes should be working together and binocular vision established. For binocular vision to occur, the two eyes must be in alignment with each other with the visual image falling on corresponding parts of the retina. (Rose, 1998, p. 77)

Because problems with the visual system do not self-correct, they must be detected and treated if there is to be substantial improvement (Rose, 1998, p. 77). There are, in fact, a variety of impairments which make up DVI.

Strabismus and Ambliopia are two of the most significant vision problems associated with DVI.

Strabismus occurs when one of the six small eye muscles controlling eye movement is weaker than the corresponding muscle in the other eye. The eyes are not held in alignment with each other, and one eye will move separately from the other. When this occurs, images sent to the visual centers of the brain cannot be merged, and the two eyes are not able to focus on one single visual image. (Rose, 1998, pp. 77-78)

According to Rose (1998), perceiving two different images confuses the brain:

...the developing brain compensates in one of two ways. Either the two eyes will each be used at different times, in which case the right and left visual centers of the brain are both stimulated to continue development, or the brain may "turn off" or ignore the visual image from the weaker eye which is out of alignment. The child begins to lose the use of the weaker eye. This condition is called strabismic ambliopia. (p. 78)

Cohen (1998) said that, "many forms and variations of strabismus exist, depending upon direction and amount of the eye turn, the number of affected nerves or muscles, and the degree to which it is associated with reduced vision" (p. 100). Strabismus has the following predictable aspects: It can cause a child to lose effective vision in the weaker eye, the two eyes may be switched on and off frequently resulting in disruption of the normal developmental process of vision, and it gets harder to

treat as the person gets older. Strabismus also leads to ambliopia.

Ambliopia is defined as diminished effective vision in one or both eyes even with proper optical correction and despite what appears to be normal retinal and optic nerve anatomy.

...it [ambliopia] is caused by lack of stimulation or disuse. Lack of stimulation or disuse may be the result of strabismus or due to some defect such as congenital cataract or drooping eyelid which covers the eye and prevents its use. Ambliopia can be eliminated and sight preserved if treated early. Other causes of eye muscle weakness include brain tumor, retinoblastoma, cataracts, eye injury, and optic nerve damage. When eye muscle weakness is suspected an eye care specialist should examine the child. (Rose, 1998, p. 78)

Cohen (1988) reports that "there is evidence that children and adults with attentional difficulties and hyperactivity exhibit inefficient eye movement patterns that interfere with visual information processing" (p. 96). This suggests that individuals with ADD or ADHD may be at increased risk of DVI, and creates a connection between eye movement and attention span problems.

Other types of DVI include non-strabismic binocular disorders. Individuals with this type of disorder often report feeling the following: Ocular discomfort, asthenopia (optical weakness, especially muscular), eyestrain, soreness of the eyes, frontal and occipital headaches and



ocular fatigue which result in an aversion to studying and reading (Boorish, 1970; Burian & Noorden, 1974).

The various conditions that comprise DVI all serve one way or another to negatively impact the visual system and its ability to process visual information. Disruptions in the development of these visual skills is what leads to DVI. The visual system is comprised of 20 abilities (Cirigliano, 1999). Chief among those abilities are:

1. Distance and near acuity: The ability to see clearly at a far distance such as 20 feet, and the ability to see clearly at a near distance such as 16 inches.
2. Accommodation: The eye's ability to adjust focus on objects with various distances.
3. Binocularity: The ability to use both eyes as a team. Proper eye alignment and coordination is necessary so that the eyes can unite two images into one (fusion), which allows an individual to perceive a three dimensional image (depth perception, stereopsis).
4. Oculomotor skills: The ability to quickly and accurately move our eyes. These skills allow us to move our eyes so we can direct and maintain a steady visual attention on an object (fixation), move our eyes smoothly from point to point as in reading (saccades), and efficiently track a moving object (pursuits)
5. Peripheral vision: The ability to see or be aware of what is surrounding us (our side vision).
6. Visual-sensory integration: After visual data is gathered, it is processed and combined in the brain with information from hearing, also called

auditory-visual integration; balance, referred to as bilateral integration/gross-motor, posture; and movement, including eye hand coordination.

7. Visual perceptual skills: The ability to organize and interpret information that is seen and give it meaning. These information-processing skills include figure-ground, form constancy, spatial relations, visual closure, visual discrimination, visual memory, and visualization.
8. Figure-ground: The ability to recognize distinct shapes from their background, such as objects in a picture, or letters on a chalkboard.
9. Form constancy: The ability to recognize two objects that have the same shape but different size or position. This ability is needed to tell the difference between "b" and "d," "p," "q," "m" and "w."
10. Spatial relations: The ability to judge the relative position of one object to another (directionality) and the internal awareness of the two sides of the body (laterality). These skills allow the individual to develop the concepts of right, left, front, back, up, and down. This is needed in reading and math.
11. Visual closure: The ability to identify or recognize a symbol or object when the entire object is not visible.
12. Visual discrimination: The ability to discriminate between visible likeness and differences in size, shape, pattern, form, position, and color. Such as the ability to distinguish between similar words like "ran" and "run".
13. Visual memory: The ability to recall and use visual information from the past.
14. Visualization: The ability to create or alter new images in the mind. It is needed in reading and playing sports.

The vision skills and abilities that can be disrupted by Developmental Vision Impairments include: accommodation, binocularity, oculomotor skills, peripheral vision, visual-sensory integration, visual perceptual skills, figure-ground, form constancy, spatial relations, visual closure, visual discrimination, visual memory and visualization (Mental-Health-Matters.com, 2004). The following list describes typical symptoms and characteristics common to those with DVI:

1. Usually male
2. Average to above average intellectual ability
3. Normal distance acuity: 20/20 accommodation/focus despite presence of ambliopia, strabismus, etc.
4. Refractive Status: Hyperopia (Farsightedness)
5. Short visual attention span
6. Reading and/or using a computer causes eyes to tear, itch or hurt
7. Jerky eye movements
8. Poor eye tracking skills, resulting in:
  - a. Loss of place when reading;
  - b. Skipping and rereading words,
  - c. Trouble copying from the chalkboard, and/or
  - d. Moving head across a page instead of moving eyes along a line of print
9. Eyes that cross or turn in and out
10. Squinting, eye rubbing, or excessive blinking
11. Blurred vision

12. Double vision
13. Focusing problems at near-point tasks, resulting in fatigue at near with periodic blur while reading
14. Light sensitivity after reading
15. Headaches, dizziness, nausea, or fatigue easily after reading
16. Head tilting, closing in on material, or blocking one eye when reading
17. Difficulty tracking moving objects
18. Misaligns letters or numbers
19. Unusual posture or moves head closely to see book or paper
20. Avoidance of near work such as reading--lack of skill in reaching and maintaining visual attention on extended near tasks
21. Seldom reads independently and inconsistent performance
22. Poor visualization, causing drawings to lack detail
23. Difficulty in language arts and spelling
24. Poor self-image
25. Poor peer relationships
26. Words, letters, and lines run together or jump around when reading
27. Poor visual discrimination, causing difficulty in distinguishing, for example, between squares and rectangles
28. Poor spatial orientation, causing the child to have difficulty relating to laterality and directionality so that he has difficulty knowing his right from his left, resulting in reversing letters and words

29. Poor visual memory, causing the child to have difficulty remembering what is read
30. Poor visual sequence, causing confusion in space and time so that the child cannot remember, for example, the months of the year
31. Poor figure-ground, causing the child to have difficulty selecting one thing from a group, such as a particular letter in a word or a word in a sentence
32. Difficulty following multiple directions
33. Difficulty concentrating or comprehending reading material
34. Persistent reversals of numbers, letters, or words after second grade
35. Writes crooked or poorly spaced
36. Poor eye hand coordination
37. Inconsistent or poor sports performance

(Cirigliano, 1999-2002, internet content, and Wheeler and McQuarrie, 1992, pp. 1-9).

These impairments can create visual stress reactions which include discomfort, fatigue, changes in behavior, altered eyesight and declining academic performance [OEP], 2005). To develop is to move from a state of pre-preparedness, as in the state before a human being achieves optimal vision, to a state of fully matured ability, as in the state of having fully matured vision capacity. The word developmental is used here to refer to the typical human

process of achieving full vision. Between pre-achievement and achievement of full vision is a series of age and experience related steps.

*Developmental Vision Impairment.*

The term Developmental Vision Impairment (DVI) describes the conditions that interrupt the normal development of visual abilities and skills, or are the result of disruption of normal visual abilities and skills, such as strabismus, ambliopia, non-strabismus binocular coordination problems, accommodative disorders, strabismic ambliopia, nystagmus and oculomotor dysfunction (Cohen, 1988). Definitions for each of these conditions and the role they play in DVI can be found in the Review of Literature (Chapter II). The term DVI excludes such impairments as congenital, age and disease related vision problems, partial loss of visual acuity or total blindness. For example, glaucoma, congenital and diabetes induced blindness, and cataracts.

The research question is, "What is the experience of having Developmental Vision Impairment?" The purpose of using these words formed into this question is to structure an inquiry into the phenomenon of DVI. The research question and its component words, as defined and structured

as above, seek to discover words, ideas, thoughts, feelings, sensations, beliefs, symbols and expressions that reveal the nature, character and details of those who experience the effects of the phenomenon identified as DVI. The next section will explore the social and clinical relevance of studying the experience of having DVI.

### *Social and Clinical Relevance*

From my own personal experience with Developmental Vision Impairment, I can draw strong inferences about the social and clinical relevance of studying this subject. In my experience, the DVI resulted for me in fear of either being physically, socially or emotionally harmed. From school performance and social development to the very core of my self-esteem, I can think of little that has not been influenced either directly or indirectly by my DVI. When social impact of DVI is considered, I am reminded that I experienced difficulty in socializing with other male children due to the impact of visual impairment on sports performance. Sports and athletic games are the staple of young, male social development activity. Therefore, my DVI negatively impacted my social development from an early age. I came to form a significant part of my self-concept around my poor athletic performance. Specific examples

include: fear of being hit by incoming balls that could strike and hurt me; fear of embarrassing myself and losing social status by reflexively shying away from the ball; and demonstrating poor passing, kicking, shooting and scoring ability, which often result in lower social ranking and status among males.

Off the playground or athletic field, my social development and self-image were further harmed by my perception that I must not be very smart if I could not read and write as fast as the children around me. In terms of social fit, I did not feel that I belonged with the "smart kids," and I did not fit in with the "dumb kids." I was a child without a social country. I believe that I made my way by finding individuals who I could socialize with in one-to-one situations. I became afraid of social groups because I could not get much experience with participating in social groups. This ultimately became a self-sustaining problem with my social development: I could not socialize with groups because I had not developed the skills, but I could not develop the skills because I was not getting practice in social groups.

The cumulative effects of these social and emotional challenges can be a significant lowering of self-esteem,



self-confidence and social ability. The end result is that an individual with undiagnosed and untreated DVI could have poor self-image, self-concept, and identity. Such a frustrated and disaffected individual can become hostile toward authority, and behave in an oppositional and defiant manner, thus creating a threat to social group cohesion and performance. Therefore, helping individuals with DVI has positive social implications for any society of which they are a part by improving their ability to participate and enhance the functioning of social groups.

Children with Developmental Vision Impairment may be frequently misdiagnosed as having Attention-Deficit Hyperactivity Disorder, Oppositional-Defiant Disorder and/or an emotional impairment, to name but a few. All of these diagnoses, which are given to people who exhibit similar behavioral symptoms to DVI, though caused by different phenomena, are associated with poor and negative outcomes in life. These outcomes include significantly increased risk for: criminal and legal problems, substance abuse, employment problems, relationship difficulties, and divorce.

In addition, there are other impacts on the individual and society stemming from each of the above difficulties

including: lost productivity, absenteeism, social discord, violence, deteriorating homes and communities, increased costs to the public through taxes needed for correction facilities. Identifying and assisting visually impaired individuals could contribute to a reduction of some of these societal ills. Inversely, helping visually impaired individuals could promote positive benefits to society. Individuals so helped could contribute to greater human good through creative, scientific and altruistic endeavors.

I realize that the worst part of my own situation by far is that I could have been helped as a child but was not. I was not properly diagnosed or treated in childhood. Neuroplasticity, the ability of the brain to generate new neural pathways which is essentially the biological foundation of behavioral growth and change, is stronger the younger a person is. By the age of 29, when I was finally diagnosed and began corrective vision therapy, I was almost too old to complete the development of vision. I was told by both my optometrist and my vision therapist that after the age of 40, it is nearly impossible to correct DVI through vision therapy. Vision therapy is the practice of using behavioral optometric strategies and exercises to

enhance the strength and functioning of vision and reduce or eliminate Developmental Vision Impairment.

Based on my personal experience, intuition, and sense of altruism, I feel strongly that helping others with this problem is the right thing to do. But how to help them is the significant question. The knowledge of Developmental Vision Impairment and its treatment have existed for a long time. Despite this, few teachers, pediatricians, nurses, school administrators, psychologists, psychiatrists or other professionals are aware of the existence of this phenomenon. Even among those in the field of vision assessment such as optometrists and ophthalmologists, the practices of assessment and treatment is limited. I personally saw no fewer than five optometrists between the ages of 8 and 29. None of them correctly diagnosed my condition, and the one who did explained that there are many in the field who remain sadly ignorant. She said that many of the profession's members do not know the problem exists, included here would be the optical technicians who work at stores that sell eye-glasses. Others do not have the necessary training or equipment to detect and diagnose the phenomenon. And there are yet others, often older professionals whose training may be 20-30 years outdated,

who do not believe that such Developmental Vision Impairments are amenable to improvement through vision therapy. In this last case, they may not seek to diagnose or advise clients about the existence of DVI. Professionals are not the only ones who could benefit from knowledge of the existence of Developmental Vision Impairment and its treatment. Parents, siblings, grandparents, aunts and uncles, and cousins could all benefit from increased awareness and understanding of DVI so that they can provide greater support and encouragement.

The first way my study can be of help is to explore the individual's experience of growing up with and having visual impairment. The second way is to bring the knowledge gained to families and professionals in the various fields mentioned above. My hope in doing so is to enhance the awareness of the existence of this problem, increase understanding of the impact it has on the individual and the family, and ultimately generate compassion toward the individual with the Developmental Vision Impairment.

Detecting Developmental Vision Impairment is difficult for parents, teachers, and even the person who has it. Clues to its existence are present long before they are ever assembled into understanding. Therefore, efforts

toward understanding, exploring, detecting and correcting this condition hold the promise of improving children's overall probability for success. Disseminating information about the existence, presence, and psychological, optometric, and educational treatment of DVI holds the promise of improving the social outcomes of afflicted individuals and the communities in which they live.

#### *Value of The Research*

The phenomenon of Developmental Vision Impairment affects a person in many areas of functioning. Therefore, many different professions must contend with it, e.g.: education, optometry and ophthalmology, neurobiology, psychology, psychiatry and pediatrics. Given that DVI impacts functioning related to these various areas, it seems logical to assume that its study and treatment are of interest to these professions. The relationships between these areas of experience within the individual and the professional disciplines which serve them are significant. A child whose Developmental Vision Impairment leads to test anxiety will suffer from lower grades which is an area of interest for parents, teachers and administrators, not to mention the children themselves.

The lower grades, resulting low self-esteem, despair and other emotional concerns will be of significance to psychotherapists, social workers, psychiatrists and parents. Pediatricians, who are prime resources for parents when determining the problems and treatments for various childhood problems, need to understand the needs of visually impaired children.

Children likely would have difficulty describing the symptoms of their Developmental Vision Impairment and; therefore, be unable to represent or explain their experience, problems or needs. They may also be reluctant to ask for the help they need because of pride, protecting their remaining self-esteem, or fear of treatment. In my experience, children do not typically favor going to the doctor if they can avoid it. I was always reluctant to submit to treatment for the challenges I faced. Doing so felt both like a loss of control and a failure to me.

If successful, this study has the potential to shed light on a previously unseen world of experience; improve the overall life capacity for success, happiness, achievement and well-being for the individuals who have a DVI, and for those around them.

For all of these fields, a greater awareness of the symptoms of Developmental Vision Impairment can lead to more accurate diagnosis. The diagnosis, in turn, can lead to clients receiving the appropriate treatment and corrective therapy. The more that is understood about the emotional, social and interpersonal experiences, challenges and needs of developmentally vision impaired individuals, the more support can be offered to them by their teachers, administrators, parents and therapists.

#### *Summary*

In this chapter, I introduced my topic of interest, and included historical information, and personal, professional and social meaning of the topic. I stated my question, explicated the relevance of studying the topic to my field and degree, and gave complete psychological definitions of terms for the question and topic. The next chapter reviews relevant literature on DVI, which creates a context for understanding the phenomenon under investigation, demonstrates the writer's expertise on the topic, and positions the proposed research study.

## CHAPTER II

## Review Of Literature

The objective of Chapter II is to review relevant literature pertaining to Developmental Vision Impairment (DVI) in order to create a context for understanding the phenomenon under investigation. Chapter contents include the databases consulted and key words used in the search process; an overview of the search's results; and an exploration of the present study within the larger context of DVI.

*Search Information*

The initial review employed the search engine Google and utilized the EBSCOHost, First Search, and Infotrac databases. These databases include peer review journal articles. Key words were: vision, seeing, vision impairment, vision development, Developmental Vision Impairment, vision impairment resources, vision impairment specialists, vision therapy, over convergence, under convergence, ambliopia, ambliopia specialists, strabismus, strabismus specialists, optometrists, ophthalmologists, eye teaming, behavioral optometry, and learning disability.

The resulting hits numbered over 70,000 for the broader and more common terms, such as vision, seeing, and vision



impairment. The more specific terms such as vision impairment and vision development resulted in a number of hits ranging from 30 to approximately 9,000. Phrases such as "convergence vision problems" resulted in hits numbering from 50 in the EBSCOhost database to 703,000 from Google. The Google search brought up websites relevant to children, education and the impact of vision impairment. Google searches for Ambliopia and Strabismus numbered in the area of 300,000 hits, and seemed to be mainly concerned with the medical diagnostic criteria for, and scientific definitions of, these terms. Several pertinent dissertations were identified, only a few of which were currently in circulation.

#### *Relevance of the Search Results*

Relevant pieces of literature on DVI were naturally and clearly divided by the professional fields from which they emanated: Optometry, education, and psychology. For the purposes of clarity, this literature review is organized around these three fields. While the overall quantity of hits for some of the key words and phrases was large, many pertaining to science and mathematics were of limited use. There appeared to be little if any experimental research on the specific topic of DVI. In terms of applicability, much

of the information yielded from the initial review of the literature was on the general subject of vision loss and blindness, and was of little or no direct use for this research study, and therefore, disregarded. However, experimental, quantitative research was found related to the self-esteem and self-concept of visually impaired or otherwise learning disabled children, e.g., optometric definitions and statistical prevalence rates; methods of diagnosis and treatment; and correlation between Developmental Vision Impairment and negative outcomes such as lowered academic performance, poor self-esteem and juvenile delinquency.

To find more literature on DVI, it was necessary to expand the search beyond terms specifically related to vision and its constituents. The expanded search yielded literature that directly connected the fields of Learning Disabilities (LD) with DVI. However, most of the literature on LD that applies to DVI does not contain any specific reference to DVI. Therefore, it was not appropriate to refer to this literature as DVI-LD literature. Instead, it was referred to as LD literature to facilitate the reader's ability to explore source material. The result of this choice is the creation of sections in this literature

review which appear to expand into the realm of LD at the expense of a tighter focus on DVI. However, the LD literature cited in this chapter has direct bearing on this study of DVI, and its presence enhances the reader's opportunity to assess the significance and meaning of findings.

A more general literature search involving words and phrases related to LD produced results relevant to psychology and education. Themes were found that connected DVI, LD, and such aspects of psychology as perception, delinquency, self-concept, self-esteem, self-efficacy, stress, their interrelationships and impact on a person's life.

In addition to locating specific research and literature on DVI, the overall review aided this study by yielding valuable information on the spectrum of existing vision impairments. Moreover, it yielded the term "Developmental Vision Impairment," and allowed for its distinction from such superficially related terms as "vision impairment, vision loss, partial vision loss, and low vision." It also provided the working definition for vision as contrasted with sight, a significant distinction as the two terms are

related and frequently regarded as synonyms, but in fact are significantly different.

Results from the initial search process suggested a logical fit with an integrative format. Many studies overlapped, e.g., articles about optometry included material about the impact of learning disabilities on education. Some articles were primarily about education and learning disabilities but contained information on the psychology of learning disabilities. In general, literature related to DVI falls under three main headings: Optometry, Education, and Psychology. Many contained all three.

#### *Optometry and DVI*

Optometry is the practice engaged in by an optometrist. An optometrist is a health care professional who is licensed to:

1. Examine and diagnose eye diseases such as glaucoma, cataracts, and retinal diseases and, in certain states in the U.S., to treat them;
2. Diagnose related systemic (body-wide) conditions such as hypertension and diabetes that may affect the eyes;
3. Examine, diagnose and treat visual conditions such as nearsightedness, farsightedness, astigmatism and presbyopia;
4. Prescribe glasses, contact lenses, low vision rehabilitation and medications as well as perform minor surgical procedures such as the removal of foreign bodies. (Medicine.Net, 2006)

It is the field of optometry that has observed, quantified, and defined the various impairments that exist under the umbrella term DVI. The review of literature on DVI thus logically begins with a review of optometric information.

### *Prevalence*

DVI is a phenomenon more common and widespread than one might expect. To begin with, as much as 20% of the population of the United States (approximately 56,000,000 people) may have some form of DVI (Azwell, 2005). Among vision impairments, DVI has a prevalence rate second only to refractive problems such as myopia (nearsightedness), hyperopia (farsightedness) and "far greater than most ocular diseases" (Cohen, 1988, p. 95).

M.C. Gould & H. Gould (2003) report that one out of four school age children have impaired vision, and according to the organization Parents Active for Vision Education [PAVE] (2004), it is estimated that more than 10,000,000 children ages 10 and younger have impaired vision at any given time. Yet, a mere 14% of children ages 6 or younger have had a comprehensive eye exam. That means, that at any given time, there are 8.6 million children ages 6 and under whose eyes have gone unchecked. Based on these numbers, it is not hard to accept that vision disorders, in general, are the fourth

most common disability in the United States and the most prevalent handicapping condition in childhood.

Cohen (1988) reports that various studies incorporating thousands of children found rates of strabismus alone to be between 4% and 8%. At 8%, the number of individuals with strabismus in this country would be approximately 23,200,000 which is more than the populations of Michigan, Ohio and Rhode Island combined. The rates for ambliopia, a DVI condition where the brain shuts down perception from one eye, range from 2% to 8.3% of the population. New cases of ambliopia in the United States approach 127,000 a year, more than 109,000 of whom do not receive a comprehensive vision exam. While some of the individuals with strabismus may also have comorbid ambliopia, the numbers when added together are staggering. Non-strabismic binocular coordination problems, another form of DVI, are reported at an even higher rate of 15% of adults.

The rates above describe the prevalence of DVI conditions across the entire population. Cohen (1988) indicates that so called "special" populations of children, e.g., those with hearing, reading, and emotional impairments, and the developmentally disabled, "...demonstrate unusually high prevalence rates of visual

problems. This is of particular importance because almost 11% of the school population has been identified as having one of the above handicapping conditions (p. 96)".

A Preslan and Novak study from 1996 citing studies conducted in Baltimore city schools found that 10% of children failed vision screening tests and follow up tests by an ophthalmologist (Rose, 1998). A study of 1,634 poverty level children in New York State found that nearly 53% failed a similar battery (Cohen, 1988). M.C. Gould & H. Gould (2003) report that 83.5% of 351 foster care children had vision problems. Such numbers indicate that DVI exists in greater numbers among children from low socioeconomic backgrounds. These numbers are also significant because, according to the 2000 Census, 20% of U.S. children live in poverty.

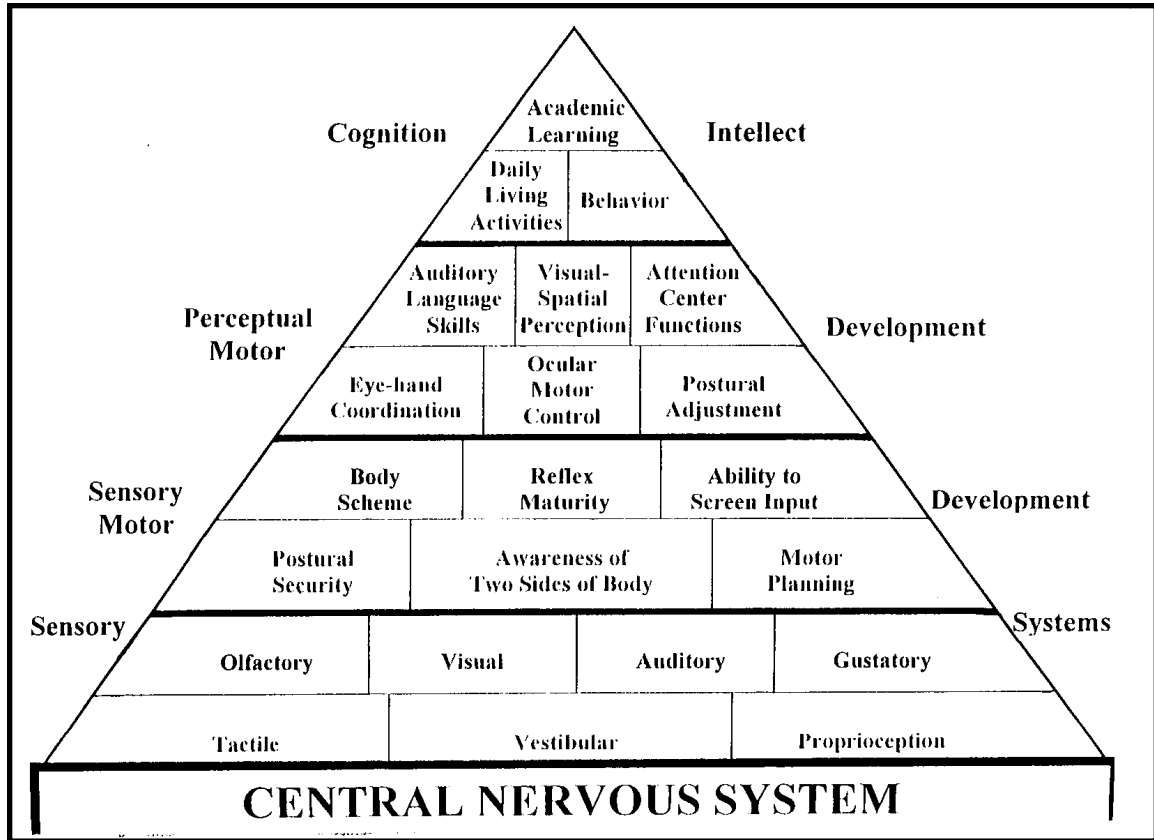
#### *Causation*

Sensory integration is a field that offers a plausible explanation for the causation of DVI: A disruption in the development of the brain and its integration of its senses. Whatever the initial cause of the non-integrated senses, i.e., teratogens (toxins such as drugs or alcohol that the developing fetus is exposed to during gestation), birth trauma such as oxygen deprivation or overexposure to

activities which fail to stimulate the senses, such as excessive TV watching, the result is impaired vision and ocular motor skills (McCarthy, 2001). The triangle (see Figure 1) demonstrates the way that specific skills and abilities such as attention functions, ocular motor control, and academic learning are derived from, or built on, the various gross sensory systems. An impairment in the visual sensory system, for example, would lead to specific problems with functionality. DVI, then, can be seen as the result of primary sensory problems involving perceptual processing and integration.



Figure 1. Skills and abilities derived from the sensory systems.



Attention-Deficit/Hyperactivity Disorder (ADHD) is a condition that produces symptoms similar to DVI, e.g., failure to pay attention in class, distractibility, frequent off-task behavior, avoidance of reading and other academic tasks, and failure to complete tasks and assignments. The similarity of the symptoms may not be a coincidence. The UCSD School of Medicine (2002) announced that of 256 individuals with ADHD, 16% had convergence disorders (difficulty with eye teaming or fusing the two images into one at the neurological level). This is roughly

three times the normal rate of convergence disorders for individuals without ADHD. This research demonstrates a newly realized phenomenon: Certain kinds of DVI and ADHD are linked. It has not yet been determined whether the relationship is causal or correlational.

One of the most significant aspects of DVI is its prevalence. DVI is a surprisingly common affliction; one that does great harm because it often goes undiagnosed and untreated. Since undetected DVI is clearly a significant problem, it is valuable to consider how it is identified.

#### *Identifying DVI*

The best way to identify a DVI is through a comprehensive vision exam. According to a press release by the Optometric Extension Program [OEP] (2005), as of 2003 only one state, Kentucky, requires by law that a child have a comprehensive vision exam. Children may experience a DVI and not realize what it is (Walker, 2004). More to the point, typical vision screenings such as those offered for free at most public schools, assess only how each eye sees at a distance. These basic vision screenings do not assess how eyes work together nor work for near-point tasks. In fact, for these basic screenings there are no strict

standards, and only 14 percent of children under age 6 have received a comprehensive eye exam (OEP, 2005).

To diagnose DVI requires an optometrist trained in behavioral optometry. However, some DVI produced symptoms can be identified by lay persons and those without behavioral optometric training, including: pediatricians, teachers, administrators, social workers, psychologists and others.

#### *Treatment of DVI*

The school environment requires the DVI individual to use underdeveloped or even nonexistent visual skills. Looking from near to far and far to near, for example, is a skill greatly impaired by DVI yet needed throughout a school day. The good news is that this skill can be improved through vision therapy (Cohen, 1988). However, for vision therapy to be effective, the treatment regimen must be followed. It has been reported that it is difficult to treat students with vision impairment because their caretakers generally do not follow up to get them to treatment (M.C. Gould & H. Gould, 2003; & Phi Delta Kappan, 2003). Non-compliant care-givers, therefore, represent a significant treatment barrier.

Treating DVI requires that educators and health care professionals be aware of the criteria and symptoms that indicate the need for comprehensive vision assessments. Rose (1998) states "teachers and health care providers may be in a position to recommend eye exam and help families to seek resources" (p. 79). Further, she points out, "Only through the cooperative effort of ophthalmologist, child, family, and teachers can the best possible visual outcome be reached" (p. 80).

#### *Education, Learning and DVI*

DVI functions as a learning disability due to the fact that it impairs the process of learning, disrupts educational activity, and leads to poor scholastic performance. The learning that takes place in formal schooling requires significant sensory processing skills. Kimple (1997) indicates that reading requires the effective use of several near-point visual skills to accomplish certain tasks. "Children who cannot perform these tasks automatically and accurately are not 'ready' for the perceptual-motor rigors of reading" (Kimple, 1997, p. 18). He also estimates that 90% of suburban children who enter

kindergarten at age 5 are ill prepared to meet the visual demands of modern schooling.

The impact of DVI on an individual's learning and education can be profound. DVI impairs the ability to learn through the sensory channel that the majority of school information is broadcast: Vision. The vision therapist Cirigliano (1999), states that two thirds of all information we receive is visual. Further, both his work and that of Wheeler & McQuarrie (1992) indicate that as much as 75%-90% of classroom learning comes through a person's visual system whereas (PAVE, 2004) and Phi Delta Kappan (M.C. Gould & H. Gould, 2003) both report the number to be 70%. Whether 70%, 90%, or somewhere in-between, clearly the amount of information that must flow from the classroom teaching into the student's brain through his visual pathways is by far the majority. Put another way, a student who only clearly absorbs 10%-30% of all classroom learning would be hard pressed to enjoy academic success or survival.

Most people never outgrow a learning disability; they merely adapt as best they can to lead the best life possible (Psychology Today Staff, 2005). It is estimated that between 2% and 10% of the population are learning

disabled (LD) (Gans, Kenny, & Ghany, 2003). That indicates a range of anywhere from 5.4 million and 29 million people with LD in this country alone at any given time. Given that DVI alone has a prevalence rate of approximately 10 million, a 2% rate of LD seems to be a low estimate.

*DVI is a Learning Disability*

Currently, the term learning disability:

...is broadly used to describe a heterogeneous group of deficits. Persons with LD have specific and severe impairments in one or more academic areas. Federal guidelines currently recommend that a diagnosis of LD be based on the severe discrepancy between scores that measure ability (i.e., IQ) and achievement in one or more of the following academic areas: oral expression, listening comprehension, written expression, basic reading skill, reading comprehension, math calculation, and mathematics reasoning. (U.S. Department of Education, 1997; Martinez & Semrud-Clikeman, 2004, Paragraph 4)

Note the exclusion of emotional considerations such as negative affect. While the exclusion of subjective, unquantifiable emotions and negative affect reduces the broad and heterogeneous group of deficits known as LD to a measurable, standardized phenomenon, it also excludes a category of symptoms that are of central importance and significance to the diagnosis and treatment of LD. LD can express itself in so many variations and varieties that it can be argued that negative affective characteristics "are major unifying dimensions of an otherwise heterogeneous

group of children" (Rogers & Saklofske, 1985, p.273).

Therefore, the presence of negative affective characteristics could be considered an integral and identifiable part of DVI.

### *Diagnosis Difficulties*

Diagnosis of LD is a difficult matter. Learning disabilities constitute an intellectual handicap that is hidden (Faerstein, 1981). This lack of visibility in and of itself impairs the detection of LD. In addition, the public school system's process for identifying, classifying, and placing students with LD frequently results in false positives, false negatives, inappropriate placements, or some combination of these (Dahbany, 2002). Misdiagnosis of DVI is common (Cirigliano, 1999) as are delayed and conflicting diagnoses, leading to belated intervention (O'Hara & Levy, 1984, as cited in Lily, 1996, paragraph 1). It is unlikely that a family member has the expertise to diagnose LD, and increased family stress levels and intolerance toward the LD child are natural results of the confusion. Diagnosis is also made harder by conflicting standards stemming from disparity between diagnostic criteria used by researchers vs that used by field practitioners (Dahbany, 2002). As a result, practitioners

in the field perceive researchers as being out of touch, and the researchers perceive those in public schools as being uninformed.

### *Motivation*

The following sections review literature on the interaction between DVI-LD and motivation. The definition of motivation, "To be motivated means to be moved to do something. A person who feels no impetus or inspiration to act is thus characterized as unmotivated, whereas someone who is energized or activated toward an end is considered motivated" (Deci & Ryan, 2000, p. 54). According to Deci & Ryan (2000), motivation can vary from person to person and from situation to situation and is both intrinsic and, or extrinsic with some overlap in the area of relatedness.

Because extrinsically motivated behaviors are not inherently interesting and thus must initially be externally prompted, the primary reason people are likely to be willing to do the behaviors is that they are valued by significant others to whom they feel (or would like to feel) connected, whether that be a family, a peer group, or a society. This suggests that the groundwork for facilitating internalization is providing a sense of belongingness and connectedness to the persons, group, or culture disseminating a goal, or what in SDT we call a sense of *relatedness*. In classrooms this means that students' feeling respected and cared for by the teacher is essential for their willingness to accept the proffered classroom values. In support of this, Ryan, Stiller, and Lynch (1994) found that relatedness to teachers (and parents) was associated with greater internalization of school-related behavioral regulations (Deci & Ryan, 2000, p.64).



The process of relatedness has great significance for DVI-LD and motivation as research indicates that having LD inclines individuals to have impaired relatedness with their teachers.

*Parents' influence on motivation.*

Parents have been found to be highly influential in LD students' development of intrinsic versus extrinsic motivation (Al-Yagon & Mikulincer, 2004; Deci, Hodges, Pierson, & Tomassane, 1992; Gottfried, 1994; Grolnick & Ryan, 1989). Mothers especially (Deci et al., 1992; Gottfried, 1994), were found to contribute heavily to children developing "positive attitudes toward school and learning, and the academic intrinsic motivation of both LD and non-LD students" (Rilett, 1998, p. 57). Families with a learning disabled child tend to emphasize more control, orderliness, and personal achievement while allowing less freedom to express feelings than families with normally achieving children (Lily, 1996). This has implications for an LD-DVI child's motivation and connects to the impact of external control by teachers.

*Motivation and learning disabilities.*

Overall, LD students tend to develop self-defeating beliefs about how and why they succeed and fail (Rilett,

1998; Pintrich Anderman, & Klobucar, 1994). Specifically, LD students frequently see the causes of their success and failure as external, i.e., due to external forces beyond their control which then lowers motivation (Rilett, 1997). Paradoxically, while LD students seem inclined to identify and locate the source of success and failure as external, they tend to translate their failures and struggles into a private self-image of being flawed (internal).

*Motivation, DVI-LD, & educational outcomes.*

The educational outcomes of LD students are negative when compared to their non-LD counterparts. More than 27% of children with learning disabilities drop out of high school compared to 11% of the general student population (National Center for Learning Disabilities, 2004). Wagner, Newman, D'Amico, Jay, Butler-Nalin, Marder, & Cox (1991) found that within 2 years of graduating from high school, 14% of LD students had entered post-secondary schooling (schooling after high school) compared to 53% of students without LD. At the 5 year mark, those numbers increased to 31% for LD and 68% for non-LD students. Post-secondary schooling includes a wide array of educational services, including vocational programs, colleges, and universities. When only four-year universities are examined, the rates

for LD students drop to between 1.3% and 3% attendance (Hall, Spruill, & Webster, 2002). Clearly, there is a significant gap between LD and non-LD students in the rates at which they succeed in education.

*Teachers' influence on motivation.*

Teachers frequently report feeling compelled to exert control over LD students who show little motivation or act inappropriately (Skinner & Belmont, 1993; Grolnick & Ryan, 1990). Such control takes the form of pushing, prodding, and overly directing the student's activities to get him or her to complete school work. The employment of control by teachers leads LD students to develop extrinsic motivation, which inclines LD students to form academically self-defeating extrinsic motivation (Rilett, 1998).

DVI interferes with learning and academic performance and therefore is a learning disability (LD). The chronic academic difficulty is a primary consequence of DVI-LD. The anxiety, depression, impaired self-concept, self-efficacy, and self-esteem that follow are secondary problems. Yet, these secondary problems have a way of taking on a life of their own. They can become an even more significant source of stress and adversity than the DVI itself.

*Psychology & DVI*

The field of psychology, despite never having specifically addressed the psychological implications of DVI, has produced a great deal of relevant literature on the psychological consequences of having LD, including the affective aspects. The results of psychological studies on LD have implications for DVI.

#### *Psychology & DVI-LD*

DVI-LD causes academic difficulty which cause feelings of powerlessness and hopelessness, promote failure, and increase stress (Olufs, 1996). Stress breaks down vision ability by putting the brain into an inefficient sensory processing state oriented toward survival (Kaplan, 2002). Thus, DVI-LD causes stress which, in turn, impairs vision, causes academic difficulty, results in more stress and, ultimately, perpetuates the cycle. Given the close connection between stress and vision impairment, it has been proposed that vision impairment and psychology are inextricably linked (Kaplan, 2002).

#### *Psychosocial Problems*

The field of psychology is concerned with the psychological and social or *psychosocial* impact of a phenomenon like DVI. A child who has difficulty processing academic information will also have substantial difficulty

interpreting, processing, and managing a constantly changing social environment (Nowicki, 2003). (Dyson 2003; Lewandowski & Barlow, 2000; and Pearl & Bay, 1999) found that children and adolescents with LD are particularly vulnerable to having social, emotional, and behavioral problems. In fact, an estimated 40% of DVI-LD individuals experience psychosocial problems (Cosden, 2001; Kavale & Forness, 1995/1996), and children with learning problems typically exhibit a higher rate of psychosocial maladjustment than do their non-learning-disabled peers (Pearl & Bay, 1999; Martinez & Semrud-Clikeman, 2004).

Children with LD are frequently described as depressed and withdrawn (Gans, Kenny, & Ghany, 2003). Mishna & Muskat (2004) cite additional studies that indicate that students with LD "report more symptoms of depression and anxiety, lower self-esteem, and greater loneliness" (Margalit, 2003/2004; Svetaz, Ireland, & Blum, 2000, Paragraph 3). Further, that LD students are "over represented with substance abuse problems (Cosden, 2001)"; that the school dropout rate of students with LD is higher which puts them at social and economic risk; that approximately 25% to 30% of LD students experience peer rejection compared to 8% and

16% of non-LD peers, and that LD students are more likely to be bullied by peers.

### *Peer Rejection*

Peer rejection is a significant source of distress for LD students. To begin with, it is common knowledge that young people are heavily influenced by their peer reference group. Mishna & Muskat (2004) observed that:

the effects of peers' negative attitudes can be so detrimental that the social problems of students with LD maybe attributed as much to peers' prejudices as to the behaviors displayed by the LD children (Pearl & Bay, 1999). Children's attitudes toward peers with disabilities are more negative than toward children without disabilities (Roberts & Smith, 1999), and research findings point to the potentially enormous impact that negative peer attitudes have upon children with disabilities. (Rose, 1998, Paragraph 9 of full text)

The unfortunate conclusion to be drawn from such findings is that LD children are viewed and treated negatively by peers as a result of their LD related behavior.

Nowicki (2003) cites long-term effects of rejection in childhood which include risk of dropping out of school, poor workplace success, and adult adjustment problems. Once it becomes a problem, peer rejection acquired during elementary school years is "a 'stubborn thing' that is relatively stable across the life span" (Vaughn, McIntosh, & Spencer-Rowe (1991).

*Psychological processes & outcomes.*

Early academic problems lead to intense emotions the child can neither manage nor protect him or herself from, thereby leading to a wish for escape during which time he or she *downshifts*. Downshifting is a closing down of thinking when the person feels overwhelmed or threatened. A stressful stimuli, e.g., inability to successfully read out loud in class, can then lead to immediate, exaggerated and inappropriate responses, e.g., acting like the class clown, temper tantrums, or misbehavior. The misbehavior can then lead to further punishment and other negative attention which enhances the sense of being under fire and leads to further acting out.

The engagement of primitive emotional fight, flight, delaying, or defensive actions make it harder for the LD child to access the higher cognitive functions (Zambo, 2003, pp. 16-17). Without access to those higher functions of cognition, planning, and self-control, the person's ability to up-shift to academically successful and socially acceptable activity is precluded. Obviously, this is a problem because high-end cognitive functions such as reading require the use of high-end cognitive faculties.

Gerber, Schnieders, Paradise, Reiff, Ginsberg, & Popp (1990) found that for nearly 25% of their respondents, the negative outcomes associated with learning disabilities worsen as the subjects reached adulthood. Further, LD adults were found to have an employment rate of only 36% (Hoffman, Sheldon, Minskoff, Sautter, Steidle, Baker, Bailey, & Echols, 1987). While overall employment rates among LD and non-LD college graduates are nearly identical at approximately 65% for LD and 75% for non-LD, there was a drastic difference between the types of jobs and amounts of money each group earned. LD college graduate employees made significantly less than non-LD college graduate employees (Audiblox, 2000a/2000b).

*Self-efficacy, self-concept, and self-esteem.*

The LD individual is inclined to form his or her self-concept from experiences of failure and the resulting negative affect caused by the DVI-LD. The resulting negative self-concept then becomes an academic death sentence because the individual expects all results in the future to match the failures of the past. He or she is therefore likely to engage challenging learning tasks with lowered motivation and effort, thus ensuring a continuation of failure and lowered sense of self (Bandura, 1977; Olufs,



1996). Impaired self-concept is exceedingly dangerous to the DVI-LD student:

Among the mechanisms of personal agency, none is more central or pervasive than people's beliefs about their capabilities to exercise control over events that affect their lives. Self-efficacy beliefs function as an important set of proximal determinants of human motivation, affect, and action. They operate on action through motivational, cognitive and affective intervening processes. (Bandura, 1989, p. 1175)

If self-concept is the picture of the self, then self-efficacy is a part of that picture. Self-efficacy, as it is described above, has a lot to do with how successful a causal agent an individual believes him or herself to be. "Self-efficacy beliefs affect the challenges that individuals choose to face, the effort they are willing to expend, and the amount of perseverance they are willing to employ" (Olufs, 1996, p. 8).

Self-esteem is the accumulated positive and negative judgments one forms about one's self concept. High self-esteem suggests that the person judges his or herself to be high in self-efficacy. Low self-esteem is the result of negative judgments about one's capacity to succeed and overall value.

It is vital to recognize the significance of the role of the self in DVI-LD. "Constructs of self-beliefs...are not mere reflections of one's past performances but are active

and agentic producers of human attainments (Bandura, 1986; Markus & Nurius, 1986 as cited in Bong & Clark, 1999, p. 139). Therefore, the self-beliefs stimulated by DVI, e.g., perception of the self as having low efficacy and value, are more than symptomatic results of the experience; they are active beliefs that can negatively effect future performance. This creates a kind of self-fulfilling proof that allows such lowered sense of self to become self-sustaining.

However, Bear, Minke, & Manning (2002) authored a meta-analysis of the self-concept research on students with learning disabilities. The meta-analysis revealed that while one would logically expect a condition like DVI-LD to cause a student to develop low global self-concept, such is not often the case. Due to the presence of mitigating factors, "children with LD may maintain favorable feelings of self-worth despite their academic, social, and behavioral difficulties" (Introduction, Paragraph 3). This finding speaks to the overall hardiness and resilience that exists in the psychological makeup of a person with LD. That is, one may see oneself as a poor student yet still evaluate oneself as fundamentally good or worthy.

A frequently asked question in the area of LD is whether being labeled as LD is helpful or harmful to the self. Nowicki's (2003) meta-analysis of studies indicates that being labeled as LD does not appear to put students at greater social risk than not being labeled. In fact, MacMaster, Donovan, & MacIntyre (2002) reported that, "self-esteem increased significantly above pre-diagnosis levels following diagnosis of a learning disability" (p. 101). These findings were consistent with Heyman's (1990) which found that higher self-esteem occurred in labeled LD children when they perceived their LD as specific and limited rather than global in nature and as treatable and modifiable. Such information could be useful to the child by allowing him or her "to displace the vague notion of 'there's something the matter with me' with a specific label, an etiology, and an authoritative description of the particular disability" (MacMaster, Donovan, & MacIntyre, 2002, p. 102).

*Attribution theory and LD.*

Attribution theory connects self-efficacy and self-concept relative to DVI-LD.

According to attribution theory, ability, effort, task difficulty, and luck are the main factors people identify as causal for both successes and failures... Research indicates that students with

learning disabilities attribute success to luck, not ability, and failure to low ability, not lack of effort (Aponik & Dembo, 1983; Buttkowsky and Willows, 1980; Diener & Dweck, 1978, 1980; Dweck & Respucci, 1973; Palmer, Drummond, Tollison & Zinkgraf, 1982; Tollefson, Tracy, Johnson, Buening, Farmer, & Barke, 1982). As the challenges become more pronounced, so do these feelings and beliefs, An increasingly external locus of control and passivity towards academic tasks develops as the students begin to "devalue their influence" over both failure and success experiences (Olufs, 1996, pp. 17-18).

Attribution theory sheds some light on how LD and DVI impact one's sense of self-efficacy, and as a result, the composition of one's self-concept and self-esteem. These core issues of self are negatively impacted by LD and can lead to what psychologists refer to as learned helplessness. Learned helplessness is a state of perception where one has extrapolated past failures as proof of the inability to succeed in the present. Thus, the affected individual is less likely to expend effort to try and succeed at something perceived to be destined for failure (Arnold, 2005), even though success can be had with effort and perseverance (Olufs, 1996). Worse yet, "learned helplessness can lead to the generalizability of decreased effort in areas which may not be directly impacted by the learning disability" (Pearl, Bryan & Donahue, 1980 as cited in Olufs, 1996, p.18).

*Families and DVI-LD.*

Not surprisingly, parents and teachers have a significant psychosocial impact on DVI-LD children.

It is recognized that there is a complex interplay among the neuropsychological deficits or strengths of a child with LD and the environment in which the child functions (Dane, 1990; Palombo, 2001). Unrecognized LD may affect the relationship between a child and others beginning in infancy. Influencing the interactions between the baby and his or her caregivers. (Mishna & Muskat, 2004, Paragraph 6 of full text)

Specifically, a child with a learning disability can present an emotional burden on the entire family. "Parents often sweep through a range of emotions: denial, guilt, blame, frustration, anger, and despair. Brothers and sisters may be annoyed or embarrassed by their sibling, or jealous of all the attention the child with LD gets" (Psychology Today Staff, 2005). According to Lily (1996), excessive amounts of time and energy expended on the LD child, and the parents' ongoing difficulty accepting the child's disability (especially in light of the parents own academic achievements) top the list of problems faced by families with LD children. Additional behavioral problems of concern to the family are untidiness and disruptive mealtime behavior, minor juvenile delinquency, and drug experimentation were reported during adolescence.

Sixty-four percent of siblings showed low understanding and patience with the LD sibling, and parents often

reported feeling guilt because they invested more time and attention in the LD child than his or her non-LD siblings. Parents also reported concern that younger non-LD siblings' achievement would embarrass older, LD siblings.

While much of the LD research explores and investigates the problems, Lily (1996) cited a surprising benefit: The presence of an LD child enhances the family's interest in personal growth and development:

Families of children with learning disabilities strive for personal growth and are active in cultural and recreational activities more than families of normally achieving children. These results suggest that the presence of a children with learning disabilities may lead to increased family emphasis upon personal growth of the family members.

This is a significant finding because it moves away from the deficit model of LD, i.e., that LD is solely a negative influence. Instead, it points out a significant, psychological adaptation, if not outright benefit.

*The deficit model.*

"The LD literature has traditionally conceptualized our understanding of LD from within a deficit model" (Martinez & Semrud-Clikeman, 2004, p. 7). The deficit being within the child rather than the fit between child and educational system. A system that is almost never investigated as the source of the student's distress, i.e. a "teacher may be

fickle, brutal and stupid, but when a child fails or cannot adjust, only the child is tested and treated" (Audiblox, 2000a/2000b).

The dominant approach to disability attributes the disability to a deficit within the individual and therefore focuses on diagnosis and treatment of the 'abnormality' (Baker & Donnelly, 2001; Barnes, Mercer, & Shakespeare, 1999), which may serve to only increase the vulnerability, sense of inferiority, and isolation of children and adolescents with LD. Alternatively, disability is considered in its social context, where the focus becomes the external obstacles and exclusion that hold back persons with disabilities. (Mishna & Muskat, 2004, Paragraph 8 of full text)

Bear, Minke, & Manning's (2002) meta-analysis supports the work of Mishna & Muskat (2004), and Martinez & Semrud-Clikeman (2004):

Differences related to instructional environments, such as frame of reference effects (e.g., Marsh, 1987), availability of social comparison cues (Marshall & Weinstein, 1984), non-contingent use of praise (Thompson, 1994), and teachers' beliefs about and interactions with students who have disabilities (Jordan & Stanovich, 2001) can differentially affect self-perceptions. These kinds of effects also vary within fairly narrow age differences. (Bear, Minke, & Manning, 2002, Discussion section, Importance of the Contrast Group on Interpretations)

Nowicki (2003) adds that more recent research has, in fact, evolved to begin looking at LD students in context (e.g. environmental and psycho-social factors). According to Jordan & Stanovich (2001), teachers with a pathognomonic orientation toward LD (the belief that the teacher cannot

help an LD student because the LD is caused by an organically based and permanent defect) are likely to react to the LD student in ways that lower the child's self-concept; e.g., reduced time spent working with LD students, avoidance of interactions related to academics. On the other hand, teachers with an interventionist orientation (which views the student as capable of succeeding if given attention, customized education, and support) are likely to interact with all in a manner that enhances the sense of self.

*Psychology, delinquency, & DVI-LD.*

Students with DVI frequently have significant academic difficulties. Wheeler & McQuarrie (1992) point to school performance as one of the most significant individual predictors of delinquency. They state:

So strong is the correlation of learning disability and delinquency that one is tempted to single it out as the leading factor in delinquency. It is not however the disability itself that results in the delinquency, but rather the academic failure and low self-esteem it precipitates. (p. 1)

Therefore, individual with DVI are at an enhanced risk for delinquency.

After years of academic and school frustration and failure have occurred, the child with DVI is vulnerable to the development of a negative self-concept. A low sense of



self-worth, self-esteem or self-efficacy may render the individual at greater risk of delinquent and self-destructive behavior.

The uncompensated learning-disabled child, ridiculed and shunned by his peers, will often pay any price for acceptance, and if this includes the use of drugs or other antisocial activity, the price seems small enough. But later, when the juvenile becomes a continual failure, all the dynamics in the making of a delinquent come into play. (Wheeler and McQuarrie, 1992, p. 1)

There are two kinds of delinquency, recurrent and non-recurrent. Non-recurrent delinquency is generally the domain of individuals who commit one or two delinquent acts and then outgrow such behavior. However, untreated learning disabilities lead to the recurrent cycle of destructive acts and ultimately poor self-esteem. Another implication of this is that once the negative self-esteem problem pattern is in place, fixing the learning disabilities involved (in this case DVI) is unlikely to resolve the psychological consequences (Wheeler & McQuarrie, 1992). It is clear then that DVI can have psychological impact on a person which can stem from having DVI and yet can take on a life of its own. Even after remediating symptoms, the psychological consequences can prove disastrous to one's sense of self. Delinquency can be viewed as an expression of the vulnerability that DVI-LD individuals have. Just as

there are vulnerabilities, there also exist significant protective factors that mitigate DVI's impact on an individual.

*Resilience and other protective factors.*

Resilience is the ability, condition, or state of successfully adapting in spite of environmental threat, psychological stressors, or physical vulnerability. A resilient person is able to handle adverse conditions and experience better than a less resilient person; he or she is able to rebound more quickly and effectively after encountering adversity and suffering (Olufs, 1996).

Olufs (1996) sites nine "in-child" factors that enhance and predict resilience. These factors were derived from the works of other researchers who are parenthetically named after each factor.

1. The presence of problem-solving skills that have qualities of flexibility and perseverance. Especially those tied to higher native intelligence. (Murphy & Moriarty, 1976 as cited in Olufs, 1996)
2. An even temperament that is mild-to-moderate in terms of emotional reaction, as well as attraction to a broad range of interests, hobbies, goals, and coupled with a curious and investigative nature. Such a temperament is more likely to protect an LD child and inspire adults to provide additional support. (Garmezy, 1991; Kauffman, Granebaum, Cohler, & Gamer, 1979; Werner, 1984 as cited in Olufs, 1996)
3. A social manner that engages peers and adults, and

inspires them to come to the LD child's assistance. Resilient LD kids are often found to have supportive, trust-based relationships with family members. When such relationships are absent, resilient LD kids tend to seek them out. (Anderson, 1994; Garmezzy, 1987; Schwarz, 1992 as cited in Olufs, 1996)

4. The ability to nurture others who are in distress, which could be a reciprocal social component connected to #3). (Anthony, 1987; Murphy & Moriarty, 1976; Moskovits, 1983; Rosenblatt, 1983 as cited in Olufs, 1996)
5. The ability to create meaning out of chaos and make sense out of one's experiences. (Murphy & Moriarty, 1976; Wolin & Wolin, 1993 as cited in Olufs, 1996)
6. The ability to maintain physical and psychological distance from abusive or neglectful parents. (Kauffman et al. 1979; Wallerstein & Kelley, 1980; Werner & Smith, 1982 as cited in Olufs, 1996)
7. An easygoing and pleasant personality similar to creative individuals who are autonomous and outgoing (males) or nurturing and sensitive (females) (Lewis & Looney, 1983; Murphy & Moriarty, 1976; Werner, 1984). The ability to use humor and adhere to moral standards can be contributing factors which could be strongly correlated with #2. (Wolin & Wolin, 1993 as cited in Olufs, 1996)
8. A strong sense of control (self-efficacy) and self-concept (Woodard, 1992, as cited in Olufs, 1996)
9. An intrinsic faith that things will work out for the best. (Murphy & Moriarty, 1976; Werner, 1984 as cited in Olufs, 1996)

High verbal skills, high self-esteem, and a "delineated understanding of the nature and course of the disorder protect LD children from psychological maladjustment outcomes (Morrison & Cosden, 1997 as cited in Al-Yagon &

Mikulincer, 2004, Paragraph 3 of full text). In addition, family factors of vulnerability and protection contribute to the LD child's psychological adjustment, including parental disappointment, family rigidity or disorganization, and family cohesion. For school age LD children, the school's readiness to accommodate the child's special needs, and social support from adults in the school, especially teachers, are factors in psychological adjustment (Al-Yagon & Mikulincer, 2004, Paragraph 4 of full text).

There are three themes that emerged from Olufs's (1996) study on Resilience in individuals with LD:

1. Even with successful individuals, learning disabilities provide a constant vulnerability or threat in day to day lives. The initial hypothesis viewed individuals with learning disabilities like rock climbers who faced an uphill battle, but who could rest whenever necessary to recoup their strength. In contrast however, they appear to be more like swimmers going against the current, who, upon taking a break, float backwards and lose whatever advantage they have attained.
2. Resilience involves an extremely active, not passive process. For students with learning disabilities, families and teachers can nurture and develop this resilience. As adults, frameworks can be developed which further enhance and maintain resilience.
3. A process occurs through which individuals with learning disabilities progress when successfully addressing a problem. Upon successful completion, this process appears to enhance resilience.

The bottom line of the research and findings on resilience is that it speaks to the vulnerability, survivability, and range of hardiness of LD individuals. As such, resilience has valuable implications for the study of DVI. It also suggests that there are ways to help individuals with DVI other than academic skills remediation. The research findings on LD and resilience indicate that it is vital to look at the context and meaning of DVI as a learning disability rather than studying DVI as a cause-and-effect problem with negative behavioral outcomes, e.g., getting low grades, or acting out in class.

#### *Overview*

##### *Implications of the Literature Review*

It is a truism that western society holds academic success to be the key to overall achievement and life satisfaction. Unproductive LD students are commonly encouraged to become productive through academic interventions (e.g. tutoring, skills remediation, external control, pressure, punishment, and reward). However, academics are not the only problem. LD individuals are also vulnerable to negative formation of self due to social and psychological stressors that result from academic

struggles. The negative affect that results from struggling with LD continues to exist even after academic symptoms have been treated.

Emotional support, attachment, and encouragement can help the LD person succeed where purely academic interventions are doomed to fail: in the realms of jobs, relationships, liking of the self, self-confidence, monetary and relationship success. Frequently with LD, the academic symptoms, which are often chronic and resistant to change, are the exclusive areas addressed for help. Doing so, however, can doom the person to the exact kind of long-term struggling and failure that one intends to help him or her avoid. This occurs because the helper, e.g., the classroom teacher, and the LD student may both feel like failures after academic interventions fail to enhance the resilience, perseverance, and motivation of the LD student. Worse than failing to help, academic assistance alone may actually inhibit the LD student's development of resilience, a key ingredient for the exact kind of success the teacher intends to help the student achieve.

Resilience and perseverance determine success even more than does academic skills and talent (Doskoch 2005). According to Hill (1987), it was Thomas Edison's

perseverance that led him to make more than 10,000 attempts before he created the first functional light bulb. During an interview midway through this process, Edison explained to a reporter that his 5,000 unsuccessful attempts were not failures, but rather the discovery of 5,000 methods that could not be used to make a light bulb. Another example of the power of resilience came from Hill's description of how Henry Ford (Ford Motor Company) required his engineers to continue working toward the development of the world's first production ready single-block V8 engine for more than 1 year despite their insistence that it was impossible.

Contrast this with the fact that many child prodigies, who are the virtual embodiment of academic skills and talent, frequently fail to live up to their immense promise as adults (Doskoch, 2005). What is missing from these gifted children's experience is having parents and educators teach them about task commitment, handling criticism, and perseverance in the face of social pressures.

If having significant academic skills and talent are not enough to cause one to achieve at high levels, then over-focusing on improving academic talents is a seriously misguided objective. The implication of this literature

review is that LD students also require social support for psychological suffering, e.g., anxiety, depression, and low self-efficacy,; social support (Nowicki, 2003); and assistance in developing character traits such as grit, determination, and perseverance.

### *The Position of the Study*

This is a foundational psychological study in the area of DVI. The purpose of such an exploration is to discover new and vital information that speaks to field application and points the way toward further research. The study of LD originated from the clinical observations of pioneers in the field which then inspired academic researchers. The current study has been conducted in keeping with the tradition of this field of research: "The whole field of learning disorders is the result of the clinical observations of astute practitioners who went on to study those observations" (Dahbany, 2002).

To the best of this researcher's knowledge, there have been no previous studies that explored the specific, subjective experiences of DVI individuals. By obtaining such data, knowledge about DVI will move beyond the descriptions of the symptomology, statistical rates of prevalence and academic and social impact. This kind of



data represents external and objective quantification and analysis of DVI. The current study adds an understanding of the internal, subjective experience of having DVI.

#### *Summary*

This chapter described the search methodology employed to conduct a review of relevant literature. Relevant literature was then reviewed to create a solid foundation for understanding the position of the study and the phenomenon under investigation. The next chapter introduces and explicates the research model used to conduct the study.

## Chapter III

## Research Model

A sound research model is needed to effectively execute this study. This chapter discusses the choice of which research model to use, the Heuristic Research Model (HR-Model), how the choice was made, and the model's theoretical foundation. A comparison is made between qualitative and quantitative research models. The HR-Model is defined and described and a comprehensive rationale for the choice of this mode is offered. The philosophical and historical roots/origins of the model are discussed, and the model's theory, concepts and processes are explained. Validity related to the HR-Model is also discussed.

*Theoretical Foundation of the Heuristic Research Model*

According to the model's progenitor Clark Moustakas (1990), the foundation of this particular HR-Model is based on the idea that:

Preliminary awareness of one's own knowledge and experience of a critical life issue, challenge, or problem enables one to begin a study of the problem or concern. As the inquiry expands, such self-knowledge enables one to develop the ability and skill to understand the problem more fully, and ultimately to deepen and extend the understanding through the eyes and voices of others. (p. 17)

Heuristic research methodology is specifically designed to aid the exploration of intense human experiences using both

the investigator and the co-researcher's points of view (Patton, 2002). The heuristic process of contacting, questioning, and exploring experience is vital to the success of the HR-Model.

"There is no substitute for experience, none at all. All the other paraphernalia of communication and of knowledge-- words, labels, concepts, symbols, theories, formulas, sciences--all are useful only because people already knew them experientially" (Maslow, 1966, pp. 45-46). Experience can be made up of thoughts, ideas, dreams, intuitive knowing and other inner material. The involvement of the primary research's inner material in the research is the defining characteristic of heuristics and this research model. The model is designed around and named after the concept of heuristics:

The root meaning of heuristic comes from the Greek word *heuriskein*, meaning to discover or to find. It refers to a process of internal search through which one discovers the nature and meaning of experience and develops methods and procedures for further investigation and analysis. The self of the researcher is present throughout the process and, while understanding the phenomenon with increasing depth, the researcher also experiences growing self-awareness and self-knowledge. heuristic processes incorporate creative self-processes and self-discoveries. (Moustakas, 1990, p. 9)

The HR-Model is a formal methodology for employing heuristic theory in research. Doing so enables the researcher to increase and deepen the knowledge that he or she can gain from a study.

The heuristic process is a way of being informed, a way of knowing. Whatever presents itself in the consciousness of the investigator as perception, sense, intuition, or knowledge represents an invitation for further elucidation. What appears, what shows itself as itself, casts a light that enables one to come to know more fully what something is and means. In such a process not only is knowledge extended but the self of the researcher is illuminated. (Moustakas, 1990, pp. 10-11)

Heuristic theory is a description of what a researcher naturally does as he or she investigates a phenomenon. By using the theory as the basis for a research model, the natural investigative process is acknowledged, accounted for, and implemented both consciously and intentionally. The theory thus becomes a tangible tool that can be described, discussed, and improved over time. It makes scientific the native processes of investigation that gave rise to quantitative science. Clearly, to understand the HR-Model, it is necessary to understand the nature and relationship between qualitative and quantitative research design. This discussion is found in the next section.

*Comparing Qualitative and Quantitative Research Models*

There are many different research models one can choose for a study. In general, they can be divided on the basis of whether a given model is qualitative or quantitative in nature. While similar in certain key respects, (e.g., both types of research design seek to increase knowledge through formal study) they are fundamentally different. The differences begin with definitions of the terms.

By quantitative methods, researchers have come to mean the techniques of randomized experiments, quasi-experiments, paper and pencil "objective" tests, multivariate statistical analyses, sample surveys, and the like. In contrast, qualitative methods include ethnography, case studies, in-depth interviews, and participant observation. (Reichardt & Cook, 1979, p. 7)

Qualitative research frequently produces findings not arrived at through the employment of statistical procedures or other methods of quantification (Hoepfl, 1997). However, creating categories or themes is, in a way, a form of quantification. In qualitative heuristic research, it is incumbent on the researcher to stay open to others' experience. In qualitative research, no preexisting theory or hypothesis is tested other than the theory inherent in the design and methodology. Instead, an area or topic of interest is explored without preconceived expectations for what information will be acquired. At the end of the study, themes, theories, and

hypotheses surface. Douglass & Moustakas (1985) compared quantitative research design with heuristic-qualitative design:

Traditional empirical investigations presuppose cause-effect relationships while the qualitatively oriented heuristic scientist seeks to discover the nature and meaning of the phenomenon itself and to illuminate it from direct first-person accounts of individuals who have directly encountered the phenomenon in experience. (Moustakas, 1990, p. 38)

The paradigms have different investigative objectives, where a quantitative researcher seeks "causal determination, prediction, and generalization of findings, qualitative researchers seek instead illumination and understanding..." (Hoepfl, 1997, Paragraph 5).

Just as the two types of research paradigms have different orientations and objectives, so do the researchers who use them. Qualitative researchers are likely to see human behavior as bound to and indistinguishable from the context in which it occurs. From this point of view, behavior has to be studied in a holistic and natural sense rather than by manipulating variables to test a hypothesis. Finally, a qualitative researcher seeks to get the feel of an experience or phenomenon. Qualitative research can be a very personal and subjective style of research, which can beg the question of

bias, reliability, and validity (San Diego State University, 2005). The researcher's procedures to address this are discussed later in the *Heuristic Theory, Concepts and Processes* section of this chapter and the section on *Ensuring Validity* in Chapter IV.

Quantitative researchers, on the other hand, are likely to argue that there is no distinction between natural and social sciences and that they should both be studied with quantitative means. Quantitative researchers are also inclined to see that natural and social sciences function on the basis of testable theories that create the ability to understand and predict outcomes based on the manipulation of variables. Social and psychological reality are therefore subject to variables in the same way that physical reality is (San Diego State University, 2005).

It is vital for the primary researcher to be cognizant of his or her preconceived beliefs regardless of which research methodology is used. Unidentified bias can lead to inaccurate analysis of data and yield tainted results. Identifying and addressing preconceived ideas is especially important in heuristic research.

Finally, quantitative and qualitative methodologies can complement one another. In the case of DVI research, for

example, qualitative data can create a basis for understanding the central, core themes and issues of having DVI. Quantitative research can enhance the value of such qualitative research by investigating the impact of various forms of treatment on scholastic and psychological outcomes. Such quantitative insight can then enhance the validity and reliability of various treatment options. The success of those outcomes can be explored, in part, with further qualitative research to ascertain significant experiential improvements for the DVI individual.

#### *Reasons for Choosing this Model*

The primary researcher chose the HR-Model for this study because it was a strong fit for both the subject matter and his natural style of learning. That is, the qualitative exploration of an experience fit with the objective of the study, i.e., to gain an understanding of the phenomenon of DVI and those who experience it. The HR-Model also fits the intentions and orientation of the primary researcher, i.e., his native methods and preferences while conducting an investigation.

The primary researcher chose a qualitative model because he wished to understand an experience through the subjective perspective of those who experience it as well



as his own. A qualitative research design facilitated this investigation with the following features (Siegel, 2005):

1. Ends with hypotheses and grounded theory
2. Emergence and portrayal
3. Researcher as instrument
4. Naturalistic
5. Inductive
6. Searches for patterns
7. Seeks pluralism, complexity
8. Makes minor use of numerical indices
9. Descriptive write-up

After the choice was made to use a qualitative model, the question facing the primary researcher was which qualitative model to use. There were several choices: The Heuristic Research Model, Phenomenology, Case Study, Action Research Design, and Grounded Theory. While the researcher could have conceivably used any of these to explore the experience of having DVI, the HR-Model was the best choice. In addition to its merits of allowing the researcher to use his inner experience as part of the study, each of the other choices has limitations relative to this study. Phenomenology would allow the researcher to explore the experience of his co-researchers but it would force him to exclude his own experience. Case Study would allow him to gather a great deal of data on the experience of the research participants, but it too would require him to omit his personal experience. Action Research Design is best

suited to test the efficacy of an intervention on a person's experience. Not enough is known yet about the experience of individuals with DVI to form an intervention. Grounded Theory is the only qualitative model that incorporates a preconceived theory and attempts to prove or disprove it. As the goal of this study is to acquire descriptive information about an experience that does not appear to have been previously studied in this manner, it would be difficult to form any theory before proceeding to research. The researcher recognizes, however, that an inherent theory has been put forth in this study by citing research and personal experience with psychological, social, and academic problems. The researcher has accounted for this inherent theory by seeking to maintain his openness to qualitative information that may contradict, alter, or amend it, and by recognizing that the objective of this research is to collect all pertinent data and knowledge possible rather than to prove or disprove the implicit theory.

The HR-Model was ultimately chosen because it has several features that make it the perfect fit for this study. It is ideal for investigating human experience, such as the experience of having DVI. Using the HR-Model allows

the primary researcher to utilize his own inner experience. This attracted the primary researcher because he has DVI and the model allows him to acknowledge and confront any resulting bias. In fact, it is his curiosity to understand both the experience of self and others that makes the HR-Model so attractive.

Using the self of the researcher may be essential in order to understand the phenomenon of DVI. Researching the experience of having DVI without using the self of the researcher in conjunction with exploration of the whole experience of the participants could be disastrous. Doing so could lead a researcher to make assumptions about the experience that lead to treatment modalities that could harm rather than help the population under investigation. For example, the following testimonial was offered by a doctoral candidate who conducted a study on learning disabilities.

I have been involved professionally with individuals with learning disabilities for over seventeen years, in my professional naivete, I had slowly developed the opinion that I understood the experience of being learning disabled. Upon listening to the narratives (of the case studies done for the research), I realized that in reality I had no clue about what it meant to live with a learning disability. As they recounted the painful situations they had repeatedly faced, tears came to my eyes as I recognized how little I understood. I experienced intense guilt for having spent so many years focusing on the academic manifestations and failing

to recognize the overwhelming global impact of a learning disability. For the first time I understood the pain. This new knowledge has forever changed the manner in which I attempt to help individuals with learning disabilities. I will no longer downplay or disregard its overall impact. Rather, I will endeavor to deal more effectively with the "whole" individual, more aggressively assessing the effect the learning disability has had upon the life trajectory, not just on school. (Olufs, 1996, pp. 247-248)

This researcher laments the fact that she thought that 17 years of observing and working with an LD population allowed her to understand the typical LD person's full experience; his or her needs, struggles, and dynamics. Upon listening to knowledge about the experience by LD individuals themselves, she realized the extent to which her lack of full understanding impaired her clinical efficacy. The results of this researcher's study cited the dangers to self-esteem, self-concept, self-efficacy, and overall success and life satisfaction that result from poorly treated LD (see Chapter II).

Finally, the primary researcher recognized a similarity between the heuristic process, where the researcher uses his or her self-awareness and self-dialogue to facilitate meta-awareness of the topic, and his own natural style of exploration. Logic and intuition both informed the primary researcher that he already engages in an informal heuristic experience of his world. He creatively blends logic and

intuition with concrete evidence and inner reflective knowing in the course of daily living. It is the recognition of this fit between model, researcher and topic that led the primary researcher to choose the HR-Model.

In summation, given the intention and purpose of the study, the needs for understanding required by the subject matter, the strengths of the Heuristic Research Model and the limitations of the other qualitative models relative to this study, and the fit between researcher and model, and model and topic, The Heuristic Research Model was elected as the most effective choice for this study.

#### *Philosophical and Historical Roots and Origins of the Model*

The formulation of the Heuristic Research Model is most directly credited to Dr. Clark Moustakas. Moustakas (1995) began to use heuristic research concepts for the first time with his studies of loneliness in 1961. He continued to develop his theories, methods, and analytic procedures over the next four decades. Dr. Moustakas has his roots in the conception of humanistic psychology during the middle of the 20th century. Having come of age at that time, he interacts with many pioneers in the fields of humanistic, transpersonal, and phenomenological psychology. Moustakas credits the works of some of these professionals as

influences on his development as a heuristic researcher and creation of the Heuristic Research Model (Moustakas, 1990). In the following section, years are included parenthetically to indicate the dates of these individual's significant publications.

In his 1990 treatise on the HR-Model, *Heuristic Research: Design, Methodology, and Applications*, Moustakas acknowledged the influence of Carl Rogers' theories and conceptual papers about the value and use of the self in psychology (1951/1957/1960/1965/1968/1969/1985 as cited in Moustakas, 1990). Rogers, considered by many to be a pioneer of humanistic psychology, states that the essential qualities of discovery are rooted in openness to and awareness of the processes of the self (1969). Moustakas draws from the work of many others whose concepts, ideas, and perspectives can all be found in Moustakas's HR-Model. For example, Abraham Maslow investigates self-actualizing people (1956/1966/1971), which Moustakas credits with launching a new realm of scientific study of human experiences. Paul Bridgeman (1950) emphasizes personal and subjective knowledge as a key component of objectivity. Martin Buber (1958/1961/1965) and Sydney Jourard (1968/1971) write about I-Thou relationships, mutuality,

self-disclosure, and mystery. Michael Polanyi (1962/1964/1966/1969/1983) details philosophical and scientific journeys into the concepts of the tacit dimension, intuition, indwelling, and validity in qualitative research. Willard Frick (1983/1987/1990) contributes important understandings regarding symbolic growth and its relationship to enhancing functions of identity and selfhood. Michael Patton (1980/1986/1990) develops the conceptual and practical application of qualitative methodology. Eugene Gendlin (1962/1978) develops methods and processes for focusing on central feelings and meanings in important human experiences. Richard Van Dusen (1973), Maureen O'Hara (1986), Philip Barrineau and Jerold Bozarth (1989) contributes knowledge of the connections between an internal frame of reference, person-centered therapy and heuristic exploration. Mike Arons (1972/1976/1977/1982/1988, etc.) helps distinguish between phenomenology and heuristics. The general works of Soren Kierkegaard (1941/1965), Edmund Husserl, and Gordon Allport (1954/1965/1968) have a general influence on the development of heuristic theory and methods. Finally, Moustakas cites the personal and professional influence of various doctoral students at the Merrill-Palmer Institute

and Saybrook Institute, including Diane Blau and Bruce Douglass, who are both currently licensed psychologists and professors (Moustakas, 1990).

*Heuristic Theory, Concepts and Processes*

In its purest form, heuristics is a passionate and discerning personal involvement in problem solving, an effort to know the essence of some aspect of life through the internal pathways of the self...When utilized as a framework for research, it offers a disciplined pursuit of essential meanings connected with everyday human experiences (Douglass & Moustakas, 1985, p. 39)

Moustakas (1990) points out that in heuristics, there is an unbreakable connection between that which stands outside of the self as an objective object, experience, or reality, and that which is inside the self, existing within the researcher as reflective feelings, thoughts, and conscious awareness. Heuristic research is a process of exploring, illuminating, and explicating of the phenomenon under investigation by incorporating the study of inner reflective material in the investigation of outer, objective reality. Heuristic inquiry is powerful because it leads to the disclosure of truth. Truth, in this case, is defined as an awareness and explication of the essence of an experience as derived from the combination of all that is: inner and outer, subjective and objective reality and knowledge.



The HR-Model itself is not defined by inflexible rules or methods, but neither it is a casual form of investigation. It is an intentional, formal, and non-linear process fueled by the primary researcher's intense curiosity and search for understanding. This energy on the part of the primary researcher is essential in order for one to engage in the exhaustive self-search that is the hallmark of heuristic investigation. It is a passionate search for understanding, knowledge and truth (Douglass & Moustakas, 1985).

In a heuristic study, "the object is not to prove or disprove the influence of one thing or another, but rather to discover the nature of the problem or phenomenon itself and to explicate it as it exists in human experience" (Douglass & Moustakas, 1985). No formal hypothesis is used, but the researcher may have beliefs or conceptions of the theme or question. His or her orientation is likely to be based on previous experience with the phenomenon, intuition, or tacit knowing (Douglass & Moustakas, 1985).

Each heuristic study is a unique exploration of a problem, theme, or experience. The actual path of the research is dictated by the researcher's natural process of

investigation. It is directed by the researcher's intuition, self-direction, self-motivation and spontaneous shifting of focus (Douglass & Moustakas, 1985). In this way, each heuristic study is like a mystery being explored: The researcher follows the clues he finds, and investigates them according to his internal sense of which ones are most significant. The objective is to illuminate that which is hidden or unknown rather than to prove or disprove a particular set of assumptions.

The use of the inner-material, knowing, and intuition of the researcher are the most definitive aspects of the HR-Model. This inner material is deliberately used in the process of investigation, data-analysis, and explication of findings. Patton (2002) states, "the reports of heuristic researchers are filled with the discoveries, personal insights, and reflections of the researchers" (p. 107). However, the use of the Heuristic Research Model is not without limitations. By using this process, there is the possibility of bias on the part of the primary researcher. The researcher's past experience, preconceived beliefs, or automatic suppositions could bias the analysis and synthesis of data. The main strategy for eliminating such bias is the primary researcher's mindfulness, awareness,

and vigilance. He must search himself for signs of pushing the data to be what he expects, and keep himself open to discover new understandings, ideas and perspectives.

In addition to vigilance against bias, the heuristic researcher faces other demands. He or she must have a passionate need to know about the research question or themes. The researcher has to let the research take him or herself over, and fully live the experience. This can be difficult because it may seem overwhelming to make one's research a constant companion; one who attends every aspect of waking, sleeping, and dreaming life. The heuristic process requires patience and trust on the part of the researcher; especially during the incubation and illumination phases. The researcher must therefore balance the drive and motivation to explore with the model's demand for openness, patience, and receptiveness (West, 1998).

Moustakas (1990) explained the heuristic research process, saying:

In heuristic investigations, I may be entranced by visions, images, and dreams that connect me to my quest. I may come into touch with new regions of myself, and discover revealing connections with others. Through the guides of a heuristic design, I am able to see and understand in a different way. (p. 11)

To facilitate such a process, the Heuristic Research Method is comprised of six key concepts and six key phases for

conducting research and analyzing data. Although the concepts and phases are presented in a linear fashion, they are used in a non-linear order. The use of concepts and processes is determined by the natural flow of the researcher's investigation. The primary researcher uses whichever step he or she needs to in order to process any and all information present, and may go back and forth between steps in a non-linear fashion. That is, he focuses when there is a felt sense to focus on, engages in self-dialogue when there is an issue to puzzle out, and incubates when he needs to let his unconscious and creative mind process and comprehend the experience.

#### *6 Concepts Of Heuristic Research*

The HR-Model emphasizes the use of the internal knowledge and experience of the primary researcher; and utilizes six concepts for working with both research participant and self-material: 1) self-dialogue, 2) indwelling, 3) tacit knowing, 4) intuition, 5) focusing, and 6) the internal frame of reference. Throughout this section, three types of experience are referenced. It is important to understand the distinctions between the three to comprehend the process and content of the HR-Model. The first type is the experience of the research participant

with the phenomenon under investigation, in this case DVI. The second type of experience refers to what the primary researcher finds when he uses heuristic methodology to explore inner phenomenon while conducting the research, e.g., his thoughts, feelings, beliefs, and felt sensations. The third type is the experience the primary researcher has while sifting through the data.

### *1. Self-dialogue*

The defining quality of heuristic research is that it utilizes the primary researcher's experience as well as that of the research participants. To access his or her own experience, the primary researcher engages in self-dialogue. "Self-dialogue is the critical beginning; the recognition that if one is going to be able to discover the constituents and qualities that make up an experience, one must begin with oneself. One's own self-discoveries, awarenesses, and understandings are the initial steps of the process" (Moustakas, 1990, p. 16).

The HR-Model is based on the premise that the only way to truly come to know and understand anything is to have some personal experience with it. Moustakas (1990) said that, "the process of self-dialogue...is guided by a conception that knowledge grows out of direct human

experience and can be discovered and explicated initially through self-inquiry" (p.17). "Procedures aimed at unearthing self-knowledge are a primary and unique feature of this model" (Bach, 2002, p. 94).

In self-dialogue, the primary researcher enters into discussion with the phenomenon. He or she must take an open and honest look at what is then found. The primary researcher asks questions of self and experience and lets inner truth, wisdom and insight provide the answers. The answers can be as concrete as thoughts and opinions, or as diffuse as impressions, feelings and sensations (Moustakas, 1990). This exploration involves the researcher shifting back and forth in a rhythmic flow from experience to words, words to feelings, feelings to thoughts, thoughts to concept, and back again to experience (Craig, 1978). The primary researcher visits this material many times during the heuristic research process. "Again and again--until one has uncovered its multiple meanings. Then one is able to depict the experience in its many aspects or foldings into core themes and essences" (Moustakas, 1990, p. 17) Self-dialogue is facilitated by four heuristic concepts and processes: Indwelling, tacit knowing, intuition and focusing.

## 2. *Indwelling*

The process of indwelling is characterized by an intense, unbroken focus on the aspects, qualities, and themes of an experience. It is a deliberate, conscious, non-linear, and non-logical activity. Indwelling is the pouring over of the details, aspects, parameters and other content that emerge in the researcher as he conducts his research. The primary researcher follows these clues, dwells in them, and examines their meanings. He or she returns multiple times to revisit the clues until fundamental insight is gained. One knows that fundamental insight has been gained when one can explicate knowledge related to heuristic learning, e.g., expressing core themes and depicting them in the composite depiction and narrative synthesis in the data analysis chapter.

Indwelling is a painstaking and deliberate process requiring patience and yielding incremental understanding. Indwelling is a turning inward to look at the parts, and gives the primary researcher experiences with the phenomenon under investigation. It is through this active searching for comprehension and meaning that he or she comes to know a phenomenon or aspect through the experience of exploring it. It is, therefore, a key phase in heuristic

research (Conlan 2000, Moustakas, 1990; Douglass & Moustakas, 1985). Moustakas (1990) describes indwelling in detail:

Indwelling...involves a willingness to gaze with unwavering attention and concentration into some facet of human experience in order to understand its constituent qualities and its wholeness. To understand something fully, one dwells inside the visible and obvious and invisible and essential factors to draw from them every possible nuance, texture, fact, and meaning. The indwelling process is conscious and deliberate, yet it is not lineal or logical. It follows clues wherever they appear; one dwells inside them and expands their meanings and associations until a fundamental insight is achieved. (p. 24)

An example of indwelling might be focusing on one's own awareness of body sensations, thoughts, beliefs and attitudes toward the quality of hope spurred by the experience of being in love. (Bach, 2002). As one dwells on these aspects, and flows from considering one to another, understanding of it grows. The more contact a person has with the inner world of self, the better one can describe it:

Indwelling on a particular facet of human experience often becomes a preoccupying feature of the researcher's daily activities. Everything may become raw material for scrutiny: relationships, dreams, bumper stickers, newspaper articles, chance encounters, casual conversations, and synchronistic events such unexpected phone call or visits...Compelling and arresting images may become gateways for greater understanding. (Anderson, 2000, p. 13)



Indwelling, combined with other heuristic steps, e.g., incubation and illumination, helps to yield the final product of the study: Narrative and creative syntheses that express, explain and makes accessible the primary researcher's insight into the experience. (Conlan 2000; Moustakas, 1990; Douglass & Moustakas, 1985).

### 3. *Tacit knowing*

To know or recognize anything one necessarily combines its focal elements, those aspects that are unseen and invisible, with subsidiary elements, those aspects that are visible and describable (Polanyi, 1964/1966). While the subsidiary elements are more visible and describable, they are not the most significant (Moustakas, 1990). In the case of driving a car, the subsidiary elements may be steering, accelerating and braking. These are the visible skills that are part of the experience. The focal elements, which in the case of the experience of driving a car may be one's level of excitement, readiness, and optimism, are important too. Together they make up the whole experience of driving a car. They could be simply added together, listed in order to describe the experience of car driving, except for one problem: The focal aspects of an experience can be

difficult or even impossible to put into words. Polanyi (1983) states:

We can know more than we can tell.....take an example. We know a person's face, and can recognize it among a million. Yet we usually cannot tell how we recognize a face we know...this knowledge cannot be put into words. (p. 4)

Tacit knowing is the combination of subsidiary and focal elements, and thus "the capacity to sense the unity or wholeness of something from an understanding of the individual qualities or parts" (Conlan, 2000, p. 117).

Accessing tacit knowing is a deliberate, conscious activity, and the tacit knowledge itself requires no conscious or deliberate effort to form.

Douglass & Moustakas (1985) said that tacit knowing is a vital element in heuristic research:

In obtaining information that will contribute to resolution of an issue, or illumination of a problem, the tacit dimension underlies and precedes intuition and guides the researcher into untapped directions and sources of meaning. Tacit knowing is a basic capacity of the self...and gives "birth to the hunches and vague, formless insights that characterize heuristic discovery. (p. 22)

The tacit dimension is the key to the discovery of knowledge (Polanyi, 1969). Seeking out and considering tacit knowing is therefore vital in the heuristic process. Further, Polanyi states that, "while tacit knowledge can be possessed by itself, explicit knowledge must rely on being

tacitly understood and applied. Hence all knowledge is either tacit or rooted in tacit knowledge" (1969, p. 144).

For knowledge to become useable by others it must be transformed from implicit to explicit. Explicit knowledge, the outcome goal of scientific investigation and study, is knowledge that can be shared with and used by others. It can be recorded and used to improve the quality of life for a person, e.g., through its application in psychotherapy, and can be used to further the area of study, e.g., by encouraging, enabling and enhancing future research.

#### *4. Intuition*

Intuition is related to but different from tacit knowing. Where as one tacitly knows about objects, experiences, and events without active intent to form the tacit knowing, intuiting the connections, patterns, and relationships between objects, experiences, and events is an active, deliberate process. Intuition and tacit knowing are connected in another way:

From the tacit dimension, a kind of bridge is formed between the implicit knowledge in the tacit and the explicit knowledge which is observable and describable. The bridge between the explicit and the tacit is the realm of the between, or the intuitive. (Moustakas, 1990, p. 23)

Intuition can be described as a kind of creative information processing and problem solving. In the view of

Bach (2002), intuition takes place quickly and out of conscious awareness. It does not require a logical progression of analysis and assembly, it is a whole that leaps into conscious awareness. This is contrasted with Moustakas (1990), who said that, "In the intuitive process one draws on clues; one senses a pattern or underlying condition that enables one to imagine and then characterize the reality, state of mind, or condition" (p. 23).

Intuition is the vital tool for integrating the pieces and their relationships into an understanding of the patterns, that comprise the experiential whole (Moustakas, 1990). To conduct scientific inquiry, one must necessarily use his or her intuition.

Every act of achieving integration, unity, or wholeness of anything requires intuition. At every step along the way, the heuristic researcher exercises intuitive clues and makes necessary shifts in method, procedure, direction, and understanding, which will add depth, substance, and essential meanings to the discovery process (Moustakas, 1990, p.23).

Because intuition is a non-logical, non-linear process, it can create breakthroughs and new understandings that no amount of logical processing can. In fact, intuition is a potent method of processing that contributes to scientific progress. Polanyi (1969) said that "great powers of scientific intuition are called originality, for they

discover things that are most surprising and make men see the world in a new way" (p. 118). From this point of view, utilizing intuition is an essential step in any scientific process that seeks to illuminate a problem, grow understanding in an area, or progress science and humanity as a whole (Conlan, 2000).

### 5. *Focusing*

Gendlin's focusing is a clinical process derived from the idea of utilizing bodily based methods of knowing (Moustakas, 1990). In the HR-Model, focusing embodies a turning in toward the self in order to find inherent understanding, tacit knowledge, and promote further development of awareness and comprehension (Bach, 2002). Focusing has a mindful, quiet, and meditative feel to it. (The Focusing Institute, 2003).

Unlike indwelling, which is an intense dwelling inside the aspects of the primary researcher's experience, focusing requires the primary researcher to identify bodily felt senses in his or her experience, and then maintain some distance. You do not dive in and dwell within it, you sit back, ask questions of it, observe it and wait patiently. You find a felt sense and by paying attention to it and waiting for it to unfold in your understanding. It

is a process of locating felt sense, waiting for word or image that describes it to surface, and then bringing both together. One does not "follow the clues," as one does when indwelling. One waits while the hidden clues come to the surface. As described by Moustakas (1990):

Focusing is an inner attention, a staying with, a sustained process of systematically contacting the more central meanings of an experience. Enables one to see something as it is and to make whatever shifts are necessary to remove clutter and make contact with necessary awarenesses and insights into one's experiences. (p. 25)

Focusing, as it is used in heuristic research, has the following concrete, procedural steps: 1) The clearing of inner space, 2) getting a handle on the question, 3) elucidating its constituents, 4) making contact with core themes, and 5) explicating the themes (Moustakas, 1990).

*1) The clearing of inner space.*

Inner space is cleared to allow the researcher to have the mental availability to focus attention on one of his or her felt senses. Clearing is done by being quiet and mindful of what is present, and then setting it aside to make room for a felt sense to be focused on (Moustakas, 1990; The Focusing Institute, 2003, Gendlin, 1978).

*2) Getting a handle on the question.*

During this phase, one focuses on a felt sense, which is usually a bodily sensation. The felt sense is likely to be unclear and hard to describe. One focuses one's attention on the felt sense without immersing in it, as in the activity of indwelling. Instead, the researcher lets there be space between his or her conscious awareness and the felt sense (The Focusing Institute, 2003). Peripheral material that comes to mind is deliberately set aside (Conlan, 2000).

The researcher asks, What is the quality of this unclear felt sense? Then the researcher lets a word, phrase, or an image come up from the felt sense itself. It might be a quality-word, like tight, sticky, scary, stuck, heavy, jumpy or a phrase, or an image (The Focusing Institute, 2003).

3) *Elucidating its constituents.*

As the researcher becomes aware of the constituent components of the felt sense, more words and images may appear in the researcher's awareness. As the researcher explores them, he or she becomes aware of the felt sense's essential constituents: The variations of perceptions, thoughts, feelings, sounds, colors and shapes (Moustakas, 1995). The researcher explores them and comes to understand

more about the origin and meaning of the felt sense. The researcher moves back and forth between the words, images, and the felt sense (Moustakas, 1990). The researcher asks, "what is it about this whole problem that makes this quality?" (Moustakas, 1990, p. 122). One then waits for the answers and understanding to emerge. Gendlin (1978) describes this as resonating, asking, and receiving.

4) *Making contact with core themes.*

Focusing is an important process in heuristic research design because it provides the researcher with a formal methodology for gaining information from felt sense. As the mind and body are connected, there is knowledge and understanding of that which is studied that is locked in the body. Focusing is a method for accessing, processing, and then coding this knowledge.

Through the focusing process, the researcher is able to determine the core themes that constitute an experience, identify and assess connecting feelings and thoughts, and achieve cognitive knowledge that includes refinements of meaning and perception that register as internal shifts and alterations of behavior. (Moustakas, 1990, p. 25)

5) *Explicating the themes.*

By following the above steps, the researcher has the chance to unearth, identify, and explore an experience's previously hidden qualities, qualities that had remained



out of conscious awareness mainly because the researcher never paused long enough to examine his experience with the phenomenon (Douglass & Moustakas, 1985). In this phase, the researcher puts the themes to words so that information about them can be stored, re-visited and used during data analysis and creative synthesis.

*6. The Internal Frame of Reference.*

The sixth and final concept is the internal frame of reference. This is in some ways the most critical and vital heuristic research concept as it facilitates all others. It is founded on the idea that the beginning of the knowledge base is personal knowledge, information and awareness (Bach, 2002). A person's most significant awareness is developed from his or her own internal exploration and attunement to and empathic understandings of others. It is this inner understanding, the internal frame of reference, that allows knowledge to be comprehended in an accurate and undistorted way.

To know and understand the nature, meanings, and essences of any human experience, one depends on the internal frame of reference of the person who has had, is having, or will have the experience. Only the experiencing persons--by looking at their own experiences in perceptions, thoughts, feelings, and sense--can validly provide portrayals of the experience. If one is to know and understand another's experience, one must converse directly with the person. One must encourage the other to express, explore, and explicate

the meanings that are within his or her experience.  
(Moustakas, 1990, p. 26)

The internal frame of reference discussed here is that of the primary researcher and the research participants. Both are absolutely essential for heuristic inquiry.

"Because it is my [the researcher's] experience that is most germane in heuristic inquiry, I must stay in touch with the innumerable perceptions and awarenesses that are purely my own, without the interference of restrictions or judgments, with total disregard for conformity or congruence" (Douglass & Moustakas, 1985, p. 47). One must value and attend to one's internal frame of reference as the primary researcher. If one does not, then one is excluding the primary source of knowledge and insight. This can only harm the research and the product it produces. It is therefore essential that the primary researcher access his or her internal frame of reference in order to acquire meaningful data.

In order to gain access to this internal frame of reference "one must create an atmosphere of openness and trust, and a connection with the other that will inspire that person to share his or her experience in unqualified, free, and unrestrained disclosures" (Moustakas, 1990, p. 26). The primary researcher has to talk directly to the

other person, and encourage him or her to express, explore, and explicate the meanings that are within. This is accomplished during the heuristic interview which is described in Chapter IV.

The question can be asked, why does one need an internal frame of reference to understand another person's experience? Why not restrict one's self to recording and analyzing behaviors and qualities that are outwardly observable, as in a quantitative study? The answer is because seeing a behavior is not the same thing as understanding that behavior. One can also ask, why not make sure that the truth that is reported is the truth that can be seen by anyone who wishes to look? One could then exclude anything that was questionable or mysterious, anything that was in part invisible to the eye. Moustakas (1990) said, "Our behavior will sometimes appear to be irrational when viewed from the outside, when observed from an external frame of reference" (p. 26). Another view on this is that:

People do not behave according to the facts as others see them. They behave according to the facts as they see them. What governs behavior from this point of view are the person's unique perceptions of himself and the world in which he lives, the meanings that things have for him. (Combs, Richards, & Richards, 1976, p. 20)

It is clearly important therefore to acquire and utilize the participants' internal lexicon of meaning, symbol, and perception in order to rationally comprehend his or her experience in an undistorted and accurate way. In addition, it is the desire to explore that which is unclear, to uncover that which is mysterious, that is at the heart of the HR-Model.

The result of gaining and using the internal frame of reference is the acquisition of a clear and accurate understanding of an experience. To do this with one person's experience would yield valuable information. To do this with many co-researchers' experiences would yield useful, common themes and concepts. This new understanding transcends a single individual's subjective experience of a phenomenon. From this, a creative synthesis of the experience of the phenomenon becomes possible. The synthesis describes the core essence of the experience under investigation. With such a synthesis, others can comprehend the significance, attributes, and meaning of an experience they may never have had themselves. The result of the research is knowledge that can be shared, used to enhance treatments, methodologies, scientific endeavors,

and even further research. It is the possibility of such gains that defines and validates the HR-Model.

### *6 Phases of Heuristic Research*

The Heuristic Research Model consists of six distinct phases. They are: 1)The clearing of inner space, 2)getting a handle on the question, 3)elucidating its constituents, 4)making contact with core themes, and 5)explicating the themes (Moustakas, 1995). While generally proceeding from initial engagement to creative synthesis, the steps are are not a strictly linear process (West, 1998).

#### *1. Initial Engagement*

In the initial engagement, the researcher discovers some compelling problem or question that he or she wishes to solve or understand. However, Moustakas (1990) makes it clear that it must be a problem or question that the researcher has had some experience with himself:

In heuristic research the investigator must have had a direct, personal encounter with the phenomenon being investigated. There must have been actual autobiographical connections. Unlike phenomenological studies in which the researcher need not have had the experience (e.g., giving birth through artificial insemination), the heuristic researcher has undergone the experience in a vital, intense, and full way--if not the experience as such then a comparable or equivalent experience. (p. 14)

The primary researcher gets in touch with his intense interest in the topic or question (Moustakas, 1990/1995).

"The initial engagement invites self-dialogue, an inner search to discover the topic and question" (p. 27). Tacit knowing and intuition are two key concepts used during the initial engagement (Moustakas, 1990). During this phase, the researcher also identifies the terms of the research question. It is also a period of free intellectual and intuitive inner discovery. The phase of initial engagement ends when a clear research question has emerged and been stated (West, 1998).

## *2. Immersion*

In the immersion stage, the researcher feels a desire to grapple with the mystery and immerse in a state of discovery. The question to be answered becomes a constant companion. It follows the researcher through days, nights and in most interactions with friends, family, co-workers, and customers. The researcher is vigilant for any reference to the question and finds these references emerging everywhere (Moustakas, 1995).

In the immersion phase, "we enter fully into life with others around our research question, and that people, places, meetings and nature all offer possible understanding of the phenomenon. It seems a common experience that suddenly everyone in our lives

coincidentally is talking about our research topic" (West, 1998). The concepts used to facilitate the immersion process include: "Spontaneous self-dialogue and self-searching, pursuing intuitive clues or hunches, and drawing from the mystery and sources of energy and knowledge within the tacit dimension" (Moustakas, 1990, p. 28). Indwelling and focusing are also useful processes during immersion.

### *3. Incubation*

The third stage, incubation, is marked by fatigue and exhaustion. The researcher has spent much energy and time immersing in the discovery process. The researcher then engages in a period of rest or distraction from the topic. Incubation is marked by deliberate "breaks and holidays," through which one retreats from the intense concentration on the topic (Conlan, 2000, p. 124). While this may seem from the outside to be a kind of breakdown in the process of exploration, it is, in fact, a crucial stage that promotes the process. It is in this rest phase that the parts of the mind outside of conscious control begin to mull and coalesce the material. It is the creative, metaphorical part of the mind which then considers the material (West, 1998). Taking a break allows these processes to proceed without interference (Moustakas,

1990). The result is the calm before the storm, the respite before the true moments of discovery and illumination emerges. (Moustakas, 1995). Incubation essentially involves resisting any deliberate attempts to use any of the heuristic research concepts. However, incubation allows the processes of tacit knowing and the outcome of intuition (Moustakas, 1990).

#### *4. Illumination*

The illumination stage is born out of the incubation. As Moustakas (1995) describes this stage, "it is a birth process, an awakening, when all at once I understand or see something I have not understood or seen before" (p. 29). Material that has been digested gives rise to creativity. Great epiphanies, insights, mental reorganizations and important shifts in perception occur and are gained. "The illumination as such is a breakthrough into conscious awareness of qualities and a clustering of qualities into themes inherent in the question" (Moustakas, 1990, p. 29). Out of fatigue and confusion, comes renewed vigor and deeper understanding (Moustakas, 1995). The illumination stage may also involve corrections of previously misunderstood concepts or meanings. The overall illumination process is one in which themes and concepts



emerge rather than one in which they are extracted from the unconscious mind (West, 1998).

### *5. Explication*

During the explication process, the primary researcher studies the individual parts of the experience; its themes, qualities, and meanings. During this phase, the primary researcher uses focusing, indwelling, self-searching, and self-disclosure with the knowledge that the internal frame of reference is critical to their understanding. Of these, focusing and indwelling are perhaps the most significant concepts for explicating a phenomenon (Moustakas, 1990). The research brings together discoveries of meaning and organizes them into a comprehensive depiction of the core themes and essences of the experience (Moustakas, 1990, p. 31). By the end of this phase, themes have been identified, and depictions, portraits, and a composite depiction are produced. Depictions, portraits, themes and composite depictions are forms of heuristically analyzed data, and are explicated and described in Chapter V: Presentation of Findings.

It is with the themes, meanings and other useful material fully analyzed, comprehended and described that

the researcher can move to the final stage, creative synthesis (Moustakas, 1995). The creative synthesis is:

### *6. Synthesis*

The final stage of the HR-Model is the synthesis, whether narrative or creative. During this time, the researcher attempts to understand and express how all of the discrete pieces of the experience fit together (Moustakas, 1990). The researcher goes beyond mere summary, recapitulation or re-assembly of the pieces back into a whole; beyond mere distillation of themes and patterns. "In synthesis, the searcher is challenged to generate a new reality, a new monolithic significance that embodies the essence of the heuristic truth [contained within an experience] (Douglass & Moustakas, 1985, p. 52)." The primary researcher seeks to understand and express the meaning, significance, and processes contained within that whole. In doing so an answer emerges to the original question of inquiry and resolves the problem which has been studied (Moustakas, 1995).

The requirements for creating a synthesis are time, space, solitude, self-reflection, and an intimate knowledge of and familiarity with the collected data (West, 1998; Moustakas, 1990). The purpose of the synthesis is to

fulfill the mandate of the HR-Model: to discover and express the knowledge of a phenomenon. This is knowledge that can only be gained through direct experience with that phenomenon, as opposed to knowledge gained indirectly (e.g., through books, reports, or seminars on the subject of the phenomenon). Unlike a purely logical synthesis, the creative synthesis draws on the creative, analytical, and intuitive faculties of the primary researcher. Moustakas (1990) declares that a creative synthesis can only be made through the use of certain creative processes:

The major concepts that underlie a creative synthesis are the tacit dimension, intuition, and self-searching. The researcher must move beyond any confined or constricted attention to the data itself and permit an inward life on the question to grow. In such a way that a comprehensive expression of the essences of the phenomenon investigated is realized. (p. 31)

The synthesis "usually takes the form of a narrative depiction utilizing verbatim material and examples, but it may be expressed as a poem, story, drawing, painting, or by some other creative form" (Moustakas, 1990, p. 32).

In the narrative synthesis, the researcher synthesizes his understanding of DVI into a comprehensive description. The narrative synthesis functions as a creative expression of the experience of DVI. Its purpose is to allow

individuals who have not had direct contact with DVI to more readily comprehend it.

In the written, narrative form, the synthesis can make use of metaphors and descriptive language (e.g., references to sights, sounds, imagery, landscapes, and sensations) to express the significance and meaning of the experience under investigation. Ideally, the synthesis makes it possible for someone who has never had the experience to understand what it might be like to have it. Through the vivid, narrative depiction the non-initiate gains insight, compassion, understanding, and may be more likely to empathize with and understand how to best serve an individual who has experienced the phenomenon.

#### *Validation of Heuristic Research*

Heuristic research is qualitative rather than quantitative; therefore, it does not produce data and results that can be validated through correlations or statistics. The question of validity is a question of meaning: Does the primary researcher's data and analysis describe and accurately represent the experience as presented by the participants? (Moustakas, 1990). The primary researcher is the final judge of whether or not the depictions, portraits, themes, and creative synthesis are

valid (Polanyi, 1969). Moustakas (1990) agrees with this, saying that it is so because only the primary researcher has engaged in a heuristic investigation of self, and seen and analyzed all the data. However, the heuristic researcher has a formal method for checking validity, "Verification is enhanced by returning to the research participants, sharing with them the meanings and essences of the phenomenon...and seeking their assessment for comprehensiveness and accuracy" (pp. 33-34). Validation is a process of visiting and revisiting data in its various forms, at all times checking to make sure there is agreement between theme, explication, creative synthesis and meaning (Moustakas, 1990).

In summary, to understand an experience, according to Douglass & Moustakas (1985), requires a "subjective process of reflecting, exploring, sifting, and elucidating the nature of the phenomenon under investigation, question, or theme" (p. 40).

#### *Summary*

In this chapter, the HR-Model and its theoretical foundation were described. Qualitative and quantitative research models were compared, and a comprehensive rationale for the choice of this model for this study was

made. A report was made on the philosophical and historical roots/origins of the model that explained its theory, concepts, and processes. The issue of validity was addressed and, in the next chapter, the methods and procedures used to implement the model for this study are discussed.

## CHAPTER IV

## Methods and Procedures

A carefully prepared plan for implementation was necessary to produce a valuable, high quality study. The purpose of this chapter is to give a detailed description of the methods and procedures the primary researcher used to implement the heuristic research model. This chapter forms a guide to the execution and actualization of the study's research goals and philosophical underpinnings. Key information in this section includes: Preparation for data collection; collection of data; organizing and analysis of data; letters and forms; and demonstration of process.

## Preparation for Data Collection

On the topic of self-search, Moustakas (1990) states that "...from the beginning and throughout an investigation, heuristic research involves self-search, self-dialogue, and self discovery; the research question and the methodology flow out of inner awareness, meaning, and inspiration (p. 11)." The primary researcher accomplished self-search through ongoing mental focus, engagement in meditation, mindfulness activities, reflective journal writing, and positive self-talk. The

Russian psychologist Lev Vygotsky believed that private speech was an advanced method of self-reflection and problem solving (Sólrun B. Kristinsdóttir, 2005).

In the process of self-talk, the primary researcher literally spoke out loud to himself. Doing so engaged a variety of exploratory and problem solving neurological processes and mental activities. Through this process he accessed his inner self, intuition and tacit knowing. He further stimulated new self-awareness through discussions with others about aspects of my experience with the research question and methodology. Specifically, he had conversations with co-workers, peers, academicians and experts in fields concerning or related to vision, perception, education, and developmental therapy.

The primary researcher prepared himself for interviews by going through an internal search in the minutes before each interview started. During this time, he focused on his purpose and intentions. He centered around the idea of doing a heuristic investigation, and committed to the process of clearing his mind of expectations, hopes and judgments. He opened himself to receive each participant's experience, views, beliefs, history, and orientation. He further committed himself to clear away all other personal



concerns of his own regarding daily life, including other activities, relationships, duties, and obligations. He became determined to engage each participant in a unique and valuable exchange, and by doing so, was able to immerse himself in his interaction with each participant.

Sometimes this focusing and clearing process was easy, but at other times the primary researcher could not immediately clear his mind and unify his attention. At those times, he focused inward on his own thoughts and emotions, and noted what ideas and feelings were present, including any needs, wishes, or desires for specific outcomes. He then labeled, attended to and managed such inner material before setting it aside. Once this was done, he centered himself through attention to his breathing. He concentrated his energy on readying himself to receive, explore and comprehend each co-researcher's experience. He then entered each interview session ready to function in the role of primary researcher. He entered most interview situations with a level of excitement that bordered on anxiety. He managed this anticipatory anxiety with ongoing self-awareness and applied self-soothing techniques. Self-soothing techniques included intentionally slowing down his breathing, labeling and dismissing cognitive distortions

while replacing them with more accurate concepts, and allowing his body to relax.

### *Selecting and Identifying Participants*

The following list describes the criteria used to identify and select research participants. The text following the list covers these points in a more detailed manner. For a participant to qualify, the following list had to be applicable:

1. Optometric diagnosis of one or more forms of Developmental Vision Impairment. Including ambliopia, strabismus, lazy-eye, over-convergence (the tendency for eyes to turn overly inward while at rest), or under-convergence or over-divergence (the tendency for eyes to rest in an overly outward position) or difficulty with eye-teaming. Different types of DVI can exist comorbidly.
2. No non-developmental forms of vision impairment (e.g., partial vision loss, blindness, cataracts; or diabetes or trauma induced vision loss).
3. Be male or female between ages 14-75.
4. Have the ability to provide rich, verbal description; demonstrated by the participant being able to hold an initial discussion about his or her DVI using descriptive language, metaphors and stories that demonstrate the presence of knowledge and experience with the investigated phenomenon, including self-awareness, self-reflection, insight, and the ability to verbalize them.
5. The presence of non-developmental forms of vision impairment, which included glaucoma, cataracts, and congenital, diabetes or head trauma related vision loss or blindness disqualified an individual from participation. The reason for doing so was that there is a marked difference between the gross impairment of

partial or total loss of the visual field and the relatively subtle experience of DVI.

6. The participant views the research as valuable and has a sincere and serious interest in participating.
7. Willing to sign consent form.

The primary researcher interviewed both males and females as relevant research indicated no significant impact of gender on DVI aspects or outcomes. He recognized that age could be a significant factor in selecting participants since individuals below the ages of 14-15 might not have enough self-awareness, self-reflection, life experience, or ability to verbalize inner experience to provide rich description of their DVI experience. He selected the age of 75 as a cutoff point on the recommendation of a local behavioral optometrist, who suggested that participants over the cutoff age would also require screening for low vision, partial vision loss, cataracts and other associated age related vision problems. A Behavioral optometrist is a specialist in the treatment of DVI.

Satisfactory levels of these capacities for self-awareness and expression were determined by the primary researcher through his intuitive awareness while engaged in preliminary contact and discussion with each candidate.

i.e., if the primary researcher experienced the individual as capable of providing rich qualitative information regarding his or her experience, then that person was deemed an appropriate candidate for the study. If the primary researcher experienced the person as unable to contribute satisfactorily rich qualitative information, the candidate was deemed unsuitable for the study.

Rich qualitative information consists of "depictions of situations, events, conversations, relationships, feelings, thoughts, values, and beliefs" (Moustakas, 1990, p. 38). This material may come in many forms, including narrative depiction, poems, stories, artwork, journals, diaries, and virtually any other form of personal representation of an experience (Moustakas, 1990). For this study, it was vital to have participants who could express themselves beyond a rudimentary recitation of the facts and events, and who could talk in more than concrete terms. Therefore, participants were chosen who could use metaphors, feeling words and so forth. An example from one such participant was his description of being in a parent-teacher meeting as like being in a court room where the judge would not accept any of your answers, explanations or testimony. Being in that situation made him feel small, threatened, and

trapped. Imbedded in such expressive metaphor and descriptive language is part of the essence of having DVI. By contrast, it would be less useful to have a purely concrete thinker who was not in touch with his or her own inner experience and might describe being in such a meeting as simply "hard" or "frustrating."

The utility of rich qualitative information is that it "enables the researcher to derive the raw material of knowledge and experience from the empirical world" (Moustakas, 1990, p.38). To this end, "Maccoby and Maccoby, 1959 as cited in Braud & Anderson (1998), recommend that the interview participant be someone with detailed knowledge or opinions to contribute" (p. 46).

Finally, the participants were able to verbalize a sincere interest in participating seriously in the study. The participants are considered by the primary researcher to be equals in the research endeavor, they are therefore referred to as co-researchers (Rubin, 2002).

#### *Participants/Demographics*

The participants ranged in age from 17 to 71 years. All but two were Caucasian, middle to upper-middle class, and functioned as students, e.g. at the high school,

undergraduate, and graduate levels, or professionals, e.g. therapist, social worker, sales and marketing, owner and operator of an engineering firm, and two college professors. One participant was fully Latino and another half Latino. All participants were educated at or beyond the high school level, received a diagnosis of DVI, and been issued corrective lenses at some point in their lives. Eight of the 13 had received some form of vision therapy, and while only one participant had received eye surgery to correct DVI, four others had been offered and declined surgery as a treatment modality.

#### *Locating Co-Researchers*

Twelve co-researchers took part in this study. They were found through one vision clinic located in suburban Detroit as well as personal networking with contacts of the primary researcher. The commonness of DVI made finding 12 research participants relatively easy. The lack of public awareness and opportunity for acquiring diagnosis of DVI could have been the greatest obstacle for locating co-researchers.

Legal and ethical issues arose related to acquiring participants and their personal information, e.g., full names and phone numbers, from the clinic's files. The primary researcher contacted the optometry clinic to

discuss issues related to privacy, and researched relevant information on the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The primary researcher then met the ethical and legal needs for privacy protection through compliance with HIPPA standards. These included disclosure of and adherence to the confidentiality protocols used in this research project (see confidentiality section below for more details). Doing so met the clinic's need for proper legal and ethical practice while supplying the primary researcher with participants.

The procedure for contacting participants was as follows. The primary researcher discussed with a behavioral optometrist at the clinic the criteria used to select research participants. The optometrist then contacted potential participants by phone, informed them of the research study, and asked if they would be interested in being contacted by the primary researcher. Those who agreed were informed that their contact information (name and phone number) would be conveyed to the primary researcher. The primary researcher then contacted these individuals, explained the purpose and process of the research project, checked to make sure interested participants fit the criteria for participation, and then scheduled interviews.

*Contacting Co-Researchers for Participation*

Individuals who agreed to participate in the research study each received two documents: The first, a synopsis of the details of the study and the requirements of both the primary researcher and the co-researcher (see Appendix A); the second, a letter to be signed that confirmed informed consent both to participate and to allow data gained from participation to be used in published works (see Appendix B).

Co-researchers were told ahead of time that they could write down any details about their experience with DVI and bring those notes to the interview. Doing so helped ensure that participants covered significant and valuable aspects of their experience. The purpose of this stimulation was to enhance the co-researchers' ability to provide rich descriptions and reflections in an organized manner.

During each interview, the primary researcher used several guiding questions (see Appendix C) as needed after asking the main question, "What is your experience of having Developmental Vision Impairment?" The term "your" was substituted for the word "the" in order to personalize the question and facilitate heuristic information gathering. Most specific questions or reflections, however,



were formulated in the live process of each interview. Questions were therefore both unpredictable and unique to the material presented by each participant. For example, if a co-researcher indicated that he had a hard time studying as a child because he was afraid he would "miss out on something good," the primary researcher could ask about what the person feared he would miss out on, or what his experience has been with missing out on things in the past. Overall, the primary researcher took an inquisitive, exploratory approach by investigating any general or idiosyncratic words, word use, ideas or body language on the part of the co-researchers. The overall purpose of this approach was to gain access to the full understand

#### *Collection of Data*

Data was collected through the heuristic interview format described in Chapter III. Data was documented with a pair of micro-cassette recorders. Two audio recorders were used to guard against possible mechanical failures. Also, with two copies, the Primary Researcher was able to send the audio tapes to a transcriptionist while keeping a backup copy for himself. This guarded against loss or damage. One co-researcher, note paper, pens, and a

recording device were present at each interview. The recording devices were displayed openly.

#### *Confidentiality Policy*

Confidentiality was ensured by removing any identifying information from all written materials concerning research participants. Each participant was instead assigned a code number that protected his or her identity. All data was kept in secured files in accord with the standards of the Center of Humanistic Studies Graduate School, HIPPA regulations, and the American Psychological Association. In addition, all identifying information was removed from analyzed data or excerpts and verbatim material from the interviews. As a result, no one could know which ideas, experiences or beliefs belonged to which participants. All records of the participants including name and contact information were kept private. This confidentiality policy was communicated to participants in the Informed Consent Form (see Appendix B).

#### *Setting*

The interviews were conducted in the quiet study rooms of public libraries. The most important quality of the setting was that it provided an atmosphere conducive to a one-to-one interview and its recording. To that end, cell

phones were turned off and all distracting noises eliminated or reduced to manageable levels. The setting was intended to provide comfort and convenience to the participant for the 1 hour to 2 1/2 hour interview.

#### *Frequency*

Each participant was interviewed once. For the purpose of insuring validity, three participants were selected and then contacted a second time to give feedback to enhance validity.

#### *How The Interviews Were Begun*

The interviews began with a simple declaratory statement that welcomed the participant, stated the purpose of the interview, and identified that the interview would begin when the recording device was activated. The primary researcher asked the participant if he or she had any questions before beginning. After answering any questions, the primary researcher stated that the recording device would now be activated. Once the recording device was activated, the primary researcher asked the research question and then conducted the interview.

#### *Encouraging Data Disclosure/How Interviews Were Conducted*

To encourage data disclosure, the primary researcher engaged participants in a friendly, open and inquisitive

manner. Body language was relaxed with an open posture, but mirrored the participants' postures at times. The primary researcher used reflective listening techniques such as repeating portions of participants disclosures. He also did validity checks in-vivo by offering his understanding of components of the participants' experience and asking questions such as "does my expressed understanding sound accurate to you regarding your experience?", "This is what I am hearing, does that sound right to you?" or, "Does my understanding fit for you?" In general, the primary researcher also encouraged data disclosure by asking questions from material generated during the interview, in order to clarify meaning and explore the depth of the participants' data.

#### *How Interviews Were Concluded*

Interviews concluded when the research participant appeared to have nothing further to add. The primary researcher would then ask if the participant had anything further to say. If not, then the primary researcher announced that the interview was concluded and thanked the participant for his or her participation. The recorders were then deactivated. Frequently, a participant would suddenly remember another thought or idea concerning his or

her experience with DVI. This seemed to take place within 30 seconds to 2 minutes of the end of the interview. The primary researcher would then reactivate the recording devices and ask the participant to continue. This stop and start process was continued until the participant had nothing further to offer. The primary researcher then thanked the participant for his or her time and goodbyes were said.

#### *Organizing and Analysis of Data*

The data gathered consists of audio recordings of interviews, and transcripts made from those recordings. The actual presentation of what data consisted of, how the primary researcher worked with each step of the model, and how the data was handled overall, is found in Chapter V: Presentation of Findings.

#### *Letters and Forms*

Drafts of letters to co-researchers and other forms are found in Appendixes A and B.

#### *Demonstration of Process*

So that the reader can gain an understanding of the process of data gathering, a complete verbatim interview is presented in an Appendix D.

*Ensuring Validity*

Validity was checked by confirming the primary researcher's understanding of each participant's experience with that participant. Ensuring the validity of the data is an essential process for all forms of research. For this study, data validity was ascertained in two ways: 1) Randomly during each interview; and 2) after data had been processed for themes, depictions, and portraits.

First, at intervals during the interview, the primary researcher shared his initial impression and understanding of each co-researcher's presented themes and experience. From this the primary researcher gained immediate, affirming or corrective feedback on the accuracy of his conceptualizations. If the participant wished, he or she was then able to contribute additional information. The validity of any new information was ascertained, and the process was repeated until the individual had nothing further to contribute.

Second, the primary researcher chose a representative sample of three co-researchers and checked for validity of the themes, depictions, and portraits. The primary researcher checked validity by asking selected co-researchers to give him feedback on whether or not their

analyzed data accurately expressed the their experience of DVI. Adjustments were then made to assure accuracy.

### *Summary*

This chapter delineated how the primary researcher implemented the heuristic research model; prepared for data collection (self-study); prepared for each interview; described materials for co-researchers, including guiding questions; indicated how potential participants were identified and criteria used to select them; the confidentiality policy and how co-researchers were prepared for interview; and described the process of data handling. The next chapter describes data analysis, organization of data by themes, and how the primary researcher worked with each step of the model.

## CHAPTER V

## Presentation of Findings

The purpose of this chapter is to describe how the primary researcher handled and analyzed the data, and reported the resulting findings. Data presented in this chapter consists of: a list of the common themes, three sample individual depictions, a composite depiction derived from the 13 interviews, three sample portraits, and a narrative synthesis of the themes. A verbatim interview can be found in Appendix D.

*Heuristic Data Analysis*

The original form of the data consisted of 13 audio recordings made during 13 interviews. The audio recordings were each transcribed verbatim, and the transcripts analyzed using the Heuristic Research Method (Chapter III). The primary researcher passed through the data many times, reading and considering the experience contained in each interview. The first pass through the data resulted in identifying the themes. The experience of finding the themes was like looking from a tall mountain top over a fertile landscape below. After soaking in the information, the details, themes, qualities and experiences emerged into the forefront.



In the beginning, I was excited, ecstatic, and hopeful. After finding themes in the first five interviews, I told myself that I was moving very efficiently. Then I crashed around interview six. I felt overwhelmed and daunted by the sheer amount of information I had yet to process. And when I thought of heuristically processing the first five interviews, I was nervous. My mind was so full of highlighted passages and individual notes that I could not comprehend how I would synthesize this data. Then I slept on it. I took an evening off of working as hard as I could and decided to "trust the process." By this, I refer to trusting the process of the heuristic research model. I awoke the next morning and felt that I was walking in a thin fog.

I could sense that something was nearby; an understanding and clarity. I closed my eyes and placed my attention on my inner noise (focusing); the jumble of thoughts, feelings, and ideas that were rattling around. When I opened my eyes and placed my hands on the computer keyboard there was nothing for a moment. And then, it all just came pouring into my mind; it was as if someone had turned on a faucet and I was filling with knowing.

I was surprised by my ability to first comprehend and then describe the essence of the experience of having DVI. I could feel myself standing in my own mind, like a reporter, able to convey substantial insight. I began typing immediately and found that my trust in the process had illuminated the experience that had so captivated me. Periods of intense investigation and attention to detail, information, and words were followed by periods of rest, of incubation and processing of data. Finally, what emerged through me was clear insight and understanding. Words and ideas came to mind that I can share with others.

While I ultimately came to enjoy the data analysis process, my initial experience with it felt like a harsh awakening. During Chapters II, III, and IV, I worked in an intense, goal oriented manner. Fueled by caffeine, I reviewed the data, almost 500 pages of transcripts, one sentence at a time. Doing so made it possible to intimately acquaint myself with the data. I went through each transcript highlighting themes and making notes. Later, during the data analysis, I found that simply putting my head down and pressing forward was insufficient for the task of Chapter V.

I took time to relax myself, which let me shift mental gears. I nurtured my curiosity about the topic, and allowed myself to daydream about and ponder the experience of having DVI. As I did this, many things became clear, and new clarity gave rise to an understanding of the significance of the analyzed data. Before I knew it, I was moving back and forth between the analysis in Chapter V and the implications, significance, recommendations, and meaning of that data expressed in Chapter VI.

### *Themes*

Themes are the essential qualities, meanings, and dimensions of the experience. Describing the themes is the beginning of the condensation and expression of the study's findings. The purpose of presenting the list of themes is to provide an overall reference guide to the study's central findings and results. What follows is an outline of the themes.

The experience of having DVI is:

1. Having no conscious awareness of having DVI.
2. Emotional and physical suffering.
3. Believing I am damaged (fundamentally flawed).
4. Struggling to adapt.
5. Re-examining my self-concept.

6. Coming to terms with DVI.

*Theme 1: Having no conscious awareness of having DVI.*

Before diagnosis or at a young age, one has no conscious awareness that his or her vision is impaired.

As a kid I had no knowledge of being vision impaired. I would take the normal tests at school, once a year they would come down and you'd look at a vision chart and I could see the letters and repeat them.

I didn't know it [DVI] was going on because it seemed very normal because I can see and I can read just fine. I couldn't really understand why I wasn't retaining information. I thought that was because I was disinterested in reading but then I am a little disinterested in my classes. I don't know, I got a little confused. This was a very confusing time.

*Theme 2: Emotional and physical suffering.*

DVI imposes suffering on a person in the form of confusion, frustration, and physical and emotional pain. Some suffering stems from aspects of the experience out of consciousness.

My experience with DVI has been very frustrating because I didn't know it was going on because it seemed very normal because I can see and I can read just fine. I couldn't really understand why I wasn't retaining information.

My DVI has been a hindrance on my reading since I was very young. It causes headaches at times and as a youngster it made me feel like I was doing something wrong because I wasn't reading like the other kids in the class were.

The fact that people would kind of giggle and I could not figure out where the ball was. Aaron, I tell you one thing that people in general cannot put up with from anybody is embarrassment when they can see it coming. You'll put up with it if you can't see it coming. But to know it's coming is very, very hard to put up with.

*Theme 3: Believing I am damaged (fundamentally flawed).*

The person with DVI comes to see him or herself as the source of the problem. Identification results in the person forming a negative self-concept characterized by perceiving oneself as deficient, unworthy, and damaged. One participant said "I thought that it must be me; I must be stupid. I literally thought that." Another revealed:

I came to the conclusion that I was kind of a dumb kid compared to the rest of the kids in my catholic school class because I really did have trouble reading.

A third indicated that he saw himself as being fundamentally different from the smart, accomplished kids, and identified the origin of his difficulties as some nebulous part of his being.

I can remember seeing the "smart kids," always huddled together. They were like a clique. I was intimidated by them because while I thought I was smart, I didn't think I was really really smart the way they were. I was ashamed of myself, and just saw my lack of being highly intelligent as a fixed quality, just a fact of life that I would have to accept. There is a lot of acceptance with DVI, you accept because the other choice is to always be upset about stuff. I just figured that I had to accept stuff like not being

smart. I also figured there was just something about me, and I didn't know what it was, but there was something about me that made me a bad student...an undesirable person. I didn't know what it was, but I connected it directly with getting poor grades and not having the teachers tell me that I was doing well.

*Theme 4: Struggling to adapt.*

The DVI individual adapts to the struggles, suffering, and visual perception problems at both conscious and unconscious levels. He or she seeks to establish self-efficacy and self-control, while at the same time defending against frustration, helplessness, fatigue, and negative self-concept.

Yes. This is not going to be good because this (athletic activity such as baseball) is going to be another freakin' disaster. My buddies are all going to laugh and I'm not going to put up with it. So I'm going to read a book. I'll be a student, a scholar; I'll be anything but not an athlete. So I did not subject myself to situations that I knew ahead of time that my eyesight would be an impairment. I've always been a scholar not an athlete. The eyesight is probably the scholarship and things close to me rather than things where binocular and depth perception is important. To that extent, I've accommodated that problem by running away.

If you can't change the facts, it's like there's a little saying, you can't change the direction of the wind but you can change the set of the sail. You can change your reaction to the wind. You can change your reaction to the facts. You can change your reaction to life. You can accept it, you can work with it, you can fight it; it's up to you how you react to the news for the day, to your wife or something like that.

One of my adaptations was that I externalized my struggles. I didn't see it as a big problem with

myself. I just thought that reading was boring so of course I'm not enjoying it. It was the reading that was flawed, not me.

*Theme 5: Re-examining my self-concept.*

Once diagnosed, the DVI individual re-explores his or her self-concept. The past is re-examined in the light of a new fundamental knowing: one's troubles were caused by a vision impairment rather than by some inherent flaw, powerlessness, worthlessness, or vague and undefinable personal failing or inadequacy. New and positive meanings and knowing are created about DVI and the self. As a result of this process, strong emotions are released, created, and rise to the surface of consciousness.

As I started to learn about vision therapy at age 50 and that's when I realized that when I was 6, 8, 10, 12, 14 that's why I was so screwed up because I couldn't see anything, couldn't judge anything, there was no connection with all of it. I wish I knew then that I wasn't just a moron and a klutz and a poorly coordinated person. There was a reason for it. I've always been afraid of heights. I hate heights and again I never realized that it had to do with balance as well as trusting my feet would hold me up because in movement I tend to lose balance. I used to call myself a wimp and a sissy, but now I look back at all that stuff and realize it was because I couldn't see.

When I first thought I might have DVI, and that it explained all of these subtle, chronic, negative experiences and struggles I had in my life, I was excited. I wanted to explore and figure things out. That was before the diagnosis. After the diagnosis, I wanted to cry. There I was, a 29 year old man sitting in an optometrist's office filled with toys for kids, and I felt like a kid again. It was all so unfair that

I struggled, and yet, it was such a relief to know. And then a kind of pride began to burn in my heart. I had made it. I had made it through all of these struggles, without any real help or assistance with my DVI. I realized then just how strong, effective, and tough I really was. I stood amazed and in shock, the tears behind my eyes were as much out of ecstatic joy as from the release of pain and a lifetime of stress.

*Theme 6: Coming to terms with DVI.*

Regret flows from wondering what could have been better if one had had early help in one's own life. There is mild to severe resentment of the teachers, parents and other experts who should have known something was wrong but did not. Simultaneously, compassion blossoms with regard to those who have gone or will go through the same struggles with DVI. A sincere wish is made to help others with DVI, especially children, to avoid going through painful suffering and damaged self-concept. Some individuals with DVI are even inclined to dedicate their professional work toward finding and helping such children.

I realize that I had to go through all of that because it has made me understand the kids who get picked on and now I am a huge advocate for these kids at school. I find them, help them find their voice. I am focused on empowering myself and others who were like me. Each time I can help somebody else it's like a vicarious healing for me of what had happened back then. Even now, when I think about what happened back then, I feel badly about a lot of it. I don't like to think about how bad it was then emotionally.

Because of the misunderstandings about myself that came from my self and others I am interested in



helping others. I have a variety of problems: Dyslexia, ADHD, this problem, that problem. I have all these different things but the one thing that changed my life is when I got to Dr. Smithe. I figured out that it was my eyes. It wasn't me; I wasn't stupid after all. I thought I was stupid because help never helped me, and you can quote me on that. But now that I know about the vision impairment, I can put my various disabilities in their place. I can figure out which problems have been caused by what disabilities. This has a very important result: Now I look at things and don't limit myself as much. It's okay for me to say no I can't do that, but just because I can't do that doesn't mean that I can't do this. I'm figuring out there's things I can do. I also understand that nobody really heard my side of the story because I couldn't explain to them why I couldn't do what I couldn't do. It isn't because I was stupid, worthless, or unworthy of being helped. I wasn't invisible because I wasn't worthy. There was just no ability on my part to make sense of what was happening to me, or to tell anyone about it. I didn't get that at the time. I thought it was all about who I was, about what was wrong with me as a person.

### *Three Portraits*

After the themes emerged, I moved on to struggle with the portraits and individual depictions. I returned to the work of Moustakas and others to ground myself in the essence of heuristic investigation. I asked myself key questions, What does a portrait and individual depiction look like? What purpose does each type of analysis serve? What is the essence of my engaging in this heuristic processing of the data? The results of this several day struggle was a clear understanding of how to complete this phase of analysis. In each of the three sample portraits,

the researcher renders an overall description of a co-researcher to place the person's experience of DVI in the context of his or her life.

*Portrait 1: participant #01.*

Participant #01 presents as a lean man of approximately 41 years; short in physical stature and yet as solid as if he were made of granite. He seems steeled by the challenges he has faced and that adaptations he has made in order to pursue success. His intensity is clearly evident, even sitting at the table he seemed poised for action and movement. His strength and power seem to be fused into his visual ability to track movement, which is one of the few visual abilities he has that has ever given him a sense of efficacy, i.e., when he could hit moving balls in sports settings. He seems determined to succeed at whatever he tried to do in life. In many of his stories is a theme of conquering his limits, and to quell the disturbance caused by some deep seated issue within his experience.

He is a married, caucasian male in his mid-40s who went most of his life without a formal diagnosis of DVI or any conscious awareness that something was wrong with his visual processing. He describes his wife as being very

bright, having no impairments to vision or learning, and able to easily do the kind of academic, reading, and socializing tasks that he struggles with. He indicates little conflict with his wife over these issues, but seems conscious of the disparity between their relative levels of ability and efficacy. Participant #01 found that his son has a similar form of DVI, but that early treatment has made a profound difference. As a result, his son does not have anywhere near the struggles or frustrations that Participant #01 had at the same age.

Participant #01 first became aware of his visual problems after nearly failing a licensing exam taken a few years before this interview. As he experienced more and more noticeable visual symptoms, he sought diagnosis and treatment. He reports significant levels of frustration with the evaluation process because the first doctors he saw were confused and unable to explain why he was experiencing any visual problems. He said that he has struggled throughout his life, and that after 3 years of searching, he finally received a diagnosis of DVI.

This participant is a man of faith, and expressed how important his faith has been in managing the difficulties associated with DVI. He took it as a significant lesson

that difficulties are to be confronted and dealt with rather than run from. He has encouraged both of his children (his second child also has DVI) to confront and overcome the limits imposed by DVI. In his own life, he has persevered through a great deal of DVI induced frustration to become an accomplished business entrepreneur. He has converted his frustration into an indomitable desire to achieve success.

*Portrait 2: participant #03.*

Participant #03 presents as a jovial, plump man in his mid-40s. He is proudly married, caucasian, and Jewish. He holds himself in a relaxed manner that conveys confidence. He comes across as warm and open-minded, and is both social and highly verbal. He frequently shares jokes, insights, and stories in an effort to connect and entertain.

Participant #03 remembers having great difficulty as a kid with reading and, at times, this made him feel like he was doing something wrong. His conclusion at the time was that he was simply an unintelligent dolt. When he started to struggle significantly in the beginning of a new year, he felt like he had lost his intelligence over the summer. He perceived his teacher as becoming hostile toward him due to his inexplicable struggles.

He was diagnosed with DVI at the age of 9 and treated with an early form of what is now called vision therapy or behavioral optometry. For a time, he had to wear an eye patch at school, which made him feel like an outcast. He said that he experienced his peers as cruel because they taunted and excluded him. At one point in elementary school, his DVI caused him to begin struggling. As hard as he tried, he slipped further behind his peers, until he perceived them as pulling ahead of him in a way that he could not catch up. He adapted to his overall sense of rejection and social isolation by developing the persona of an entertainer.

Through humor and comedy, participant #03 was able to find a method of connecting with others that simultaneously afforded him a sense of control and emotional safety. Yet he was aware of the difficulties this social separation caused. For example, he noted awareness that early on in his life his comfort in intimate relationships was affected. He says that his experiences with vision impairment led him to develop a personality to protect himself from other people. He also knows that he built his character around getting through and over life's hurdles

and challenges. He is who he is because of the struggles with DVI.

Participant #03's regret and resentment are clear as he talks about his experience with DVI. He expresses anger at the teachers and professionals who did not know how to help him or support him during his struggles. He also gets "pissed off" because he could have accomplished so much more in a career had he been helped in time. He said that if they had known what was going on and fixed it, the chances are he would have become a doctor. These strong feelings are balanced by an equally strong streak of self-determination and commitment to enjoy life on his own terms. His wish for others is that they be helped to develop who they are rather than be changed; that a person should be helped to build his or her self around strengths and personal interests rather than be compelled to be someone whom they are not.

*Portrait 3: participant #05.*

Participant #05 is a married, caucasian female in her early 50s. She presents with tremendous energy, not in terms of activity, but in terms of presence. Sitting with her is like sitting in a wind tunnel as her focus shifts

rapidly from one topic to the next. Her speech is pressured as if an internal motor drives her forward.

Participant #05 has a sadness about her when she speaks of her early experience of having DVI. She can recall vividly social torment at the hands of other girls. Frequently this was because, despite her tallness, she was fabulously uncoordinated. She could never hit the ball and spoke of being the last picked in every gym class. She refers to her experience in sports activity as horrendous; the most "god awful" experiences of her life. Although the events described are in the distant past, the feelings stimulated by early aggression directed against her are still alive. Tears come to her eyes, her jaw clenches, and her face flushes. She says that she has always struggled with a sense of being invisible to others; that people ignored her and her struggles. From that she retains a deep and multi-layered sense of low self-worth and personal fault.

Embarrassment reigns as she recalls early frustration and a sense of disempowerment. She concluded then that she was simply "a moron and a klutz." This participant goes on to describe her adult experience of finding her diagnosis of DVI 10 years ago. Learning what had been wrong with her

has brought perspective and relief. She understands why she struggled, and now she can treat herself with compassion. She understands herself in a way she could not before.

Two thoughts are dominant. The first is clear when she describes her own growth and realization that her calling is to help kids so they do not have to suffer as she did. The second is in describing her daughter's fearlessness and superior ability in diving practices and competition. While she has worked hard to grow beyond the early emotional struggle, it is clear that the suffering of her past haunts her in the here and now.

### *Three Individual Depictions*

Each of the three individual depictions below describe a co-researcher's experience using the language, themes, qualities, and individual examples drawn from his or her experience of the phenomenon. Depictions are presented in the first person point of view, and serve here to illuminate the way that the themes fit into each person's experience.

#### *Individual depiction 1: participant #08.*

Up until the end of high school which was last year, my experience with having DVI was mostly confusion. It seems like the experience of having DVI is more



subconscious because you don't see it happening and it's like you don't see through anyone else's eyes but your own. It's like you can't see through my perception and I can't see through yours so my vision I always thought was normal for me. Because of this point of view, I figured that having a hard time reading a book wasn't about how I see, it must have to do with something else.

It was just like for a long time there's only one opinion about it which is either you're lazy or you have Attention-Deficit/Hyperactivity Disorder (ADHD). That is what everyone said and I didn't want to disbelieve what everyone else has been telling me this whole time. I was convinced that I was lazy and had ADHD so it's like even if this eye thing exists, it's not really the problem. It just didn't seem possible that all those people and teachers could be wrong.

When I found out I had DVI I found it hard to accept or really comprehend what that meant. All of a sudden I had to rethink about the way I had looked at myself for every time I hadn't done an assignment or finished a book. There were a lot of work habits and rationalizations I had made because of not being able to see properly that still had to be undone and reworked. DVI was a definite kind of root of

the problem, but the fact that I saw it is a superficial thing maybe made it a little bit harder to accept.

I was also confused about whether or not the eye therapy was a real therapy or the eye problem a real eye problem. I mean, nobody else had ever heard of this before, they all thought it was something else, and now all of a sudden there is this one doctor who can detect and treat it with this weird system of lenses and pictures? I was skeptical that DVI was the answer that explained all of my problems and struggles.

My classmates would come to me to get answers and information because they were like hey, this guy is smart! But they wouldn't include me in the project group because hey, this guy doesn't ever read! One girl actually said that I am just naturally smart but lazy!

I was surprised to find out later that books aren't hard work for everyone. I assumed that reading was incredibly hard and everybody else had some superhuman ability or kind of book intelligence that I didn't have. It made me feel weak by comparison.

Before the diagnosis, I didn't know what was causing all my problems, but if you keep asking for an answer then you eventually try to make an answer. I answered the

question of what was causing my problems by defining myself as one who has low efficacy; who cannot do. And I had to do this. I had to come up with an answer because everyone pushes you to come up with one. I remember being called into meetings where the teachers and my parents were there and everyone just kept asking why I didn't do the work. They were probably trying to help me, but to me it felt like I was on trial. It's kind of like an emotional trap because you feel bad either way, there is a real paradox because the teacher says "I don't want excuses" but they want to know why things didn't get done. Any reason I could give them they interpreted as excuses. You say you don't know why you didn't do it, they insist that you did. I don't know. You have to know. I don't know. I can look back on that now and see how that's not necessarily a trick question when you're younger because they're really trying to figure out what's wrong. When it seemed like to me they were just trying to berate me. In general, it was really frustrating.

Teachers tried to give me solutions like using a day planner, and they would say try this, the day planner worked for me so it should work for you. I said that it didn't work for me because the coping strategy doesn't

work. Help that doesn't really produce a helpful outcome just proves your original theory that something is wrong with you, and makes you feel like, great, once again I tried to make things better and failed. Its better not to try. I don't even know what I am coping with. Am I coping with laziness? How do you cope with laziness? Then you try the coping strategy and it doesn't work, and you give up on it, and they get mad at you either for just not succeeding with, or utilizing in good faith, their miracle cure. Then, I tried to do "the right thing". I would step up and say, there is no real reason, I just didn't do it, and I will take responsibility; then they get mad because they call that an excuse too. But something else happens too: Taking responsibility for giving up feels true, feels honest, and you have a sense of control and power.

I look back and realize that I got so tired of always trying and failing and then feeling bad, or giving up and not trying and failing and feeling bad, that I just started to move on. I would just not get that upset about my struggles. That worked for me and gave me a measure of feeling I was in control, it was an adaptation. But it alarmed my teachers who just thought I was giving up. It drove them crazy and they would go ape on me trying to get

me to be upset that I wasn't succeeding. Eventually, after years, you just don't get that worked up about it, and your appearing calm just makes them so mad at you. I believed, before the diagnosis of DVI, that the only way this is going to be fixed is if I have some internal major epiphany and I stop being lazy.

*Individual depiction 2: participant #10.*

I have always had difficulties in school and nobody could ever put their finger on it and nobody could ever tell me what it was; and I've been tested by the school system maybe every other year. My parents wouldn't support me as I looked into my problems, so I had to persist on my own to find the help and get myself to the assessments. A family friend helped me compel my mother to get me tested and it turned out that I had disabilities in reading, writing, spelling, and math. My left eye will start at the first word and then it will stop and pause at every single word until it gets to the end of the line. My right eye will look at the first word, go all the way across and wait at the last word for the left eye to catch up.

Normally, I would be so frustrated trying to actually perceive the words that by the end there was no energy to comprehend what the information was. So I always had

trouble deciphering what things were and how to basically transition from words to what they actually mean. But while this was happening, I was totally unaware of my eyes struggling and shutting down. I didn't know what was happening or why, I just knew that reading was horrible, I used to hate to read. I hated it more than anything I hated. My teachers didn't intend to emotionally harass me, they weren't trying to do it, but it's just something you do to yourself. I always felt pressured from everything. I was always anxious, and I was always frustrated.

I adapted to my reading problems by getting books on tape and listening to them, watching movies based on the book we were supposed to read, and in grade school, I would just flat out invent material. No one ever checked my work, no one ever detected that I was covering up this huge problem. I always felt like I had to keep up with everybody. I learned to fool people into thinking I could do it and they never caught on that I couldn't. I always felt like I wasn't allowed to get behind. I won't take classes that are considered elements, or basic. I will take the regular classes. I felt anxious and pressured by the thought that I might get called on to read in front of the class and wouldn't be ready. I fooled them into believing

that I was fine. That there is nothing wrong with me. That's why they had a lot of trouble deciphering what was wrong with me at a young age because despite struggling, I gave the appearance that I could choose to keep up.

Every time the school system tested me I was able to get by so they said that nothing was wrong. It's kind of sad; it's horrible that I have to go through that many years of schooling with that many struggles. It is horrible that I have to do this on my own, but it's definitely a strength that I can do it and I'm not sitting back and waiting for somebody else to step up and give me what I need.

I see things in black or white; either it's right or wrong, I can't find the middle, and right is always defined by the successful outcomes that everyone else who is normal gets. I have to perform at an A or B level to be happy. When I get an assignment, I get frustrated, nervous and afraid that I'll forget about it. I never felt like I could be thought of as below them. I have to try twice as hard as normal kids just to keep up with them.

I get into conflicts with people constantly, especially with teachers and the administration. I have to fight to do things my way so that I can succeed because

normally everybody else's way doesn't work for me. I advocate for myself, I get things for myself that I need to get. My friends and peers have complained because they see me getting extra time for tests, something I had to fight for just to get a level playing field, and they see it as me getting an unfair advantage. The special needs room teacher even tried to kick me out because she said I wasn't struggling and other people were more in need than me. It was absolutely ridiculous for her to have the nerve to say that to me. How can she tell me what I have and haven't been through when she doesn't know a thing about me? She has no idea what I've been through. She has no idea that my parents don't support anything I try to do to improve myself or help myself.

I can't tolerate wasting my time in a class where there is no way for me to succeed. I found ways to go around what was allowed; to do it my way, but I won't cheat. I only ever cheated in one class because success was impossible. The teacher wouldn't teach the material and I couldn't read the book, and I couldn't get excused from the class, so I did what I had to do.

I cannot grasp the concept of sitting through a class and not getting anything out of it. That is just a waste of



time. I can verbalize really well but my writing is a mess. I'm verbal, I have to tell everybody if I'm not happy with something. That's how I get my frustration or my emotion out because writing doesn't work. I can't write. It's frustrating because verbally I can communicate exactly how I feel, but on paper no. When I reread things I've written and haven't seen for a while I often cannot even understand what I was trying to explain.

Life with DVI is a constant fight so I feel if I keep pushing that fight will sooner or later either weaken, slow down, or won't be as intense. I guess you could say that I have a more open mind toward people than the majority of people do. Just because I know what it's like to be on the other side and be looked down upon because I have a learning disability. LD is something society looks down upon. I fight against society. I don't think its right that I should have to fight for these things.

*Individual depiction 3: participant #13.*

It is hard to distinguish the effects of DVI with all the other factors that figure into my developmental life. The problem I had in relation to vision comes from textbook reading. While initially I read very fast, I was having trouble perceiving what I was reading. The last part of the

word seemed to come before the first. I had trouble comprehending what I was reading, and as a result, I came to the conclusion that I was a dumb kid. However, I was against the idea of accepting the role of being a dumb kid so I did my best to cover my reading problems. I actually went as far as avoiding situations where I had to read publicly, like in the classroom. I would stay up late at night sometimes, under the covers with a flashlight before school, to be sure I had covered what I would later have to read. I read ahead to memorize so that when called upon by the teacher, I could give the appearance of really reading. As a result, I developed a very agile memory. I also sought to cover the fact that I was stupid and that I didn't want to appear stupid so the conviction of my identity had to do with covering this real obvious problem. I had a psychic scar that I wanted to conceal, a psychic wound that I didn't want to be oozing in public. You are trying to pretend that you were somewhat more skillful at something that was important than you were.

My school performance was what was regarded as fairly irregular because despite my brightness and energy I was frustrated with a lot the learning demands on me. I was confrontational with my teachers, for example, in the

fourth grade, when I was 9, I was taught by a catholic nun whose name I was able to slightly mispronounce as Sister Mary Camel Ass. She and I got into a great deal of conflict and I thought she was an evil bitch. I would also refuse to speak when she cornered me and demanded I answer class questions. When I transferred from Camel Ass's class to another sister, one who was kind and gentle, I started to do better in class. Other kids would copy off of my papers, which I found to be a fairly grand gesture for my somewhat shaky self image and ego. Later, at age 11 I took a more positive view of my self after receiving a diagnosis of DVI from an optometrist.

My English and reading grades still suffered and so I was sent to a guy who had a background in English. He and I used to get along rather well and talk about existential philosophy and other kinds of intriguing issues. When I was younger, I also compensated for my reading difficulties by sitting in front of the radio 4 or 5 hours a day the way kids these days sit in front of a television. Despite my reading problems, I valued reading; there are fairly a lot of exotic, interesting things packed away in books. Another result of my difficulties with reading is that I developed my verbal communication skills. By high school, I had

become a fairly excellent public speaker, and the administration invited me to MC various gatherings and assemblies. I could remain cool while speaking to hundreds of adults at the various assemblies and pep rallies.

However, there are implications that resonated through my sense of self and self-image in a more or less permanent way. If you've never been embarrassed and humiliated in front of your peers on a regular and daily basis then you may have greater self-confidence. I had been shamed in front of my peers despite my being bright and smart enough to know that I should be able to succeed. As a result, there is probably an issue of lowered self image that persist. When I became a college professor, I used to keep a decent sized cardboard box in my office so that when they finally uncovered the fact that I was really faking it all this time, that I could just load my shit in a box and be out the door. I was haunted by a demon of success and failure, and I had always sought to cover over my failure. Because of this I never felt like I fully deserved the success I achieved, and always feared I would be found out and rejected. This demon impacted on my sense of achievement and sense of risk. I learned to bring to bear a great deal of resources to help me keep up with academic

reading, I developed a kind of a nice skill at being a velvet tongued charmer with the high school women. I had learned to act confident and project confidence in a way that others probably identified me with, but which was probably an external activity. However, being confident on the outside didn't change the fact that inside I was handling life by flying by the seat of my pants. That makes it all kind of scary because you can't just find a formula that shows that you're going to be successful. While I felt like a fraud in my early career as a professor, I found the experience of being professionally tenured and accomplished did a lot for my self-image and reduced my overall level of hostility. It was the actual, concrete, and material experience of success that allowed me to improve my self-image.

There was a moment in which I got a decent teacher and I got my eyes checked. Before, I was not in a position to reverse this problem that reading had generated in my life. The tangible solution came through in time for me to be able to apply my internal skills and the characteristics of my personality and character that figured into it. But had that not happened, had I never been able to get past the visual thing then the rest of it would have all suffered.

I've had a lot of success from my failures. In the sense that failure added the kind of energy it takes to succeed. In the end, it is smarter to adapt to DVI by learning what you can do with the world and with yourself as opposed to not having to ask those questions. I struggled, but not all of my struggles were bad. Struggles are not always bad; how they turn out depends on what your reaction is to them. If you accommodate them, become curious about what is happening to them, then they can open up and break bad mental patterns of behavior and self-image. If they shut down and try to avoid awareness and adaptation of their limitations then they are steering themselves badly through life in a self-defeating way.

#### *Data Handling*

After analyzing the data for themes, portraits, and individual depictions, I found myself feeling as if I had just laid a concrete foundation for my analysis. But the ground before me was still earthen and raw. I had all of this brilliant analysis in terms of themes, portraits, and individual depictions; 43 pages of it. I perceived the nature of the process: To continue distilling down all of the data, and the analysis of that data, until its very essence is all that remains. I envisioned that composite

depiction would be the next stage for condensing the data. As I started to work on the composite depiction, I found myself engaged in a non-linear process. I would begin in one section of the composite depiction only to find myself drawn to a quote of an individual depiction. As I moved quotes around I felt a tension between two choices: Move through my material in a linear way that would ensure I covered everything, or follow my instincts, my knowing that I should jump from one part of the overall data to another. The tension was released by my surrendering to the heuristic process, and trusting that by continuing my exploration in the way that felt best, and least stressful, I would eventually cover everything. I started to also wonder at the mystery: That I might discover understanding of DVI by moving in a non-linear heuristic research methodology that a purely linear analysis might never yield. I also recognized my own perfectionism: The part of me that wants my data analysis chapter to be perfect; the part that wants 100% validity and will settle for nothing less than perfect. I noticed, as I worked on the composite depiction that I was revisiting the themes, clarifying and refining them, continuing to bring the themes into alignment with the composite depiction.

At times during the analysis phase of Chapter V, I came to points of confusion. I was literally lost in terms of what I was doing. At those moments I chose to refocus by meditating on the purpose of Chapter V in general, and specifically on the purpose of the composite depiction. The result was getting in touch with the purpose, and feeling suddenly on track again. I knew my purpose, my mission, and my identity as a researcher. The composite depiction is my opportunity to speak for those with DVI. The content of my presentation should be an explanation of the themes of the experience. I thought immediately of Dr. Seuss's character, The Lorax, whose job was to speak for the trees because they had no voice.

I felt excitement as I illuminated that which had been invisible. I knew that I was doing so through an amazing, organic, investigative process. However, there were moments of significant frustration; moments when my analysis would grind to a halt. I felt blocked from progression as if barred by an invisible wall. The more I tried to push through these instances with energy and desire, the more stuck I became. I strategized about how to handle and overcome my frustration. Eventually, I considered a new possibility: That my blocks were not mere annoyances to be



dispatched or destroyed. Rather, they were blocks because there was a problem left unsolved. As I pursued this line of thinking, I found that there were in fact gaps in my analysis. I chose to explore those gaps by considering the inconsistencies across various parts of my heuristic analysis of DVI.

Simultaneously, I moved from my computer desk to my couch, and transferred the relevant, obstructed and obfuscated materials from digital light coming from my computer screen to printed hard-copy. I recognized at once that doing so created a shift in my perspective looking at the experience of DVI. I tacitly knew that such perspective shifting is an essential part of the HR-Model. I felt myself moving on the right track, and, encouraged, continued my data analysis. The result was that I developed my understanding of the experience of DVI. I could better and more effectively recognize its central themes and constituent ideas. In a concrete way, my shift resulted in a shifting of organizational structure.

Up until this point, I was recognizing the themes of DVI by their relatedness. I had placed material on similar or related aspects of DVI in close physical proximity. After my shift, my presentation of findings communicates

the essence of experiencing DVI, in part, by taking the reader on a tour through the various themes. The themes arise in stages as the DVI individual ages, matures, and reaches certain developmental milestones, such as being diagnosed with DVI and the reorganization of self-concept that results.

### *Composite Depiction*

The composite depiction synthesizes the themes and phenomena from the individual depictions. The purpose of the composite depiction is to search for commonality and universality among individuals' unique and subjective experiences. The composite depiction points the way to understanding a more general and universal nature of the phenomenon.

While analyzing the data, it became clear that there exists a process of development. That is, the participants' experience of having DVI unfolds over time. Each participant described a similar overall journey from unawareness that they even had DVI, to a life of challenges, struggling, and, ultimately, adaptation. I choose to present the data analysis in a similar format in order to most accurately reflect the participants' experience of having DVI. The result is a composite

depiction that serves as a tour through the experience of having DVI. As the reader progresses, he or she will follow along with the experience of having, consciously recognizing, and coming to terms with DVI. In this way, the reader's understanding of the experience of having DVI is enhanced by a temporally and developmentally grounded experience of his or her own. It is hoped that the parallel will enhance the meaning and value of the data.

The experience of having a Developmental Vision Impairment covers the life span of the individual. It is present from the beginning and increasingly impacts the person. As the tasks demanded of the person outstrip his or her ability to adapt, the subjective stress, difficulty and frustration increases. It influences the interaction between the individual and his or her environment, the reactions of which permeate the perception of self, and therefore affects how the individual sees him her herself in the world, and how he or she responds to that world.

Overview.

What follows is a more detailed outline of themes in the Composite Depiction.

The experience of having DVI is:

1. Having no conscious awareness of having DVI.

2. Emotional and physical suffering.
  - a. emotional suffering
  - b. physical frustration
  - c. participation/reading impairment
  - d. boredom and confinement
  - e. loss of options and goals
  - f. social problems
3. Believing I am damaged (fundamentally flawed).
  - a. the trouble with help
  - b. avoiding being weak
  - c. protectiveness
4. Struggling to adapt.
  - a. false self
  - b. perseverance
5. Re-examining my self-concept.
6. Coming to terms with DVI.

*Having no conscious awareness of having DVI.*

Nearly all of the participants began their response to the research question by indicating that they began life with no conscious awareness of having any kind of vision impairment until the moment of diagnosis with no awareness that they have DVI. For some of the participants, this state of unknowing stretched into the person's 20s, 30s, and 40s.

Well, the story I would have is that I had no idea I had it [DVI].

I had no idea I had it [DVI]. I didn't know that it existed. Nobody knew that I had it. Most people know that the hurdle is in front of them, I never knew it was there.

I didn't even really think I had anything until I started working with my behavioral optometrist. It never dawned on me that I might have some kind of vision impairment going on.

I wasn't aware. I wasn't aware of it [DVI] but I knew that I had a problem but I wasn't aware of really what kind of problem it was.

The primary theme has to do with how one perceives the experience of having the condition. One sees how he or she sees, one perceives how he or she perceives: one knows no other way. Therefore, there is acceptance of that which is there from the beginning; it is the way things are "meant to be."

The lack of awareness of having DVI leads to challenges, struggles, stress and suffering of a chronic nature. Simultaneously, however, the DVI individual functions without the knowing that a visual disorder exists. As will become clear, the inability to perceive DVI amplifies and exacerbates the frustration, struggling and suffering of those who have it. Even with a diagnosis, however, it can be difficult for a child to understand the significance of DVI or make connections between chronic difficulties, stress, and academic and social struggles with having a visual impairment.

When I was young I had a form of strabismus; probably not totally but I think they called it a lazy eye or something like that. No one ever said anything about a

visual impairment. I really was not aware of having DVI. I didn't know that I was visually impaired.

Individuals with DVI report frequent and chronic confusion and frustration. Part of it seems caused by the visual impairment itself, but another part comes from the schism between having a seemingly undetectable problem and the apparent struggles and suffering that result from the undetectable problem.

My experience with DVI has been very frustrating because I didn't know it was going on because it seemed very normal because I can see and I can read just fine. I couldn't really understand why I wasn't retaining information. I thought that was because I was disinterested. I was a little confused; this was a very confusing time.

The individual with DVI is aware that things are hard, or relatively harder than it seems they should be compared with others.

Having DVI was very frustrating. I didn't know it was going on because it seemed very normal because I can see and I can read just fine. I couldn't really understand why I wasn't retaining information and now it's just the biggest thing for my glasses. I'll read a sentence and then forget it right after. I thought that was because I was disinterested but then I am a little disinterested in my classes—I don't know I got a little confused. This was a very confusing time.

Confusion and frustration come from the schism between conscious and unconscious awareness. The symptoms breach into conscious awareness, yet they do not lead one to the conscious conclusion that there is a vision impairment.

It seems like the experience of having DVI is more subconscious because you don't see it happening and it's like you don't see through anyone else's eyes but your own. It's like you can't see through my perception and I can't see through yours so my vision I always thought was normal for me. Because of this point of view, I figured that having a hard time reading a book wasn't about how I see, it must have to do with something else.

As stated earlier, the experience of DVI leads to limitations, struggles, stress and suffering. There is significant value in careful exploration and expression of this material. The quality, meaning, and type of suffering give insight into the variety and commonality of the experience of having DVI.

#### *Emotional and Physical Suffering*

Having DVI resulted in many forms of struggling and suffering: e.g., physical, social, academic, and inter and intrapersonal, i.e., one's view of and relationship with one's self. These areas can be considered to be the domains in which DVI affects those who have it.

#### *Emotional frustration.*

Academic frustration frequently is a synonym for emotional frustration. DVI students are constantly confronted with visual tasks such as reading that prove seriously frustrating.

It was hard for me to really read and study-study. Even now I have that problem because of this

overlapping of lines drives me crazy. It's like you're reading the words over and over again. If I'm reading a book sometimes I will realize that I've missed a sentence and I have to go back and re-read it. It's like I'm looking down at it and it's very tiring for me now. It makes me feel tired when I'm reading because I'm struggling sometimes.

This participant also indicated that she loves to read and is an avid reader of books that stimulate her curiosity. In her case, these are books about psychology and human development.

There are many limitations and forms of suffering, but all can lead to a level of emotional frustration that overpowers a DVI student. The following verbatim research interview segment vividly illustrates the point.

Aaron: I'm curious because you said frustrated a couple of times. I think I have an idea of what you mean but I wondered like if you can describe it in another way.

Participant #06: Everything is piling on. It just all builds up and then one day I just break. It seems like an ongoing pattern of just breaking down one day and crying and then I just happen to pick myself back up. That's how it was because nothing was getting better.

Aaron: It's like no matter how hard you tried?

Participant #06: I was just like snowballing down.

Aaron: So that's something new to imagine that the experience is like breaking down underneath the weight of all the frustration. You mention crying. What would a typical breakdown look like?



Participant #06: I would start freaking out. I'd get really stressed and I'd say that I'm not going to get this paper done, I don't understand this, I'm going to fail all my classes. I even find myself saying if I don't understand it I can't do it. There's a lot of I can't do it kind of stuff.

Aaron: Are you good at visualizing failure?

Participant #06: Visualizing failure?

Aaron: I mean visualizing this picture that I'm not going to be able to do it.

Participant #06: I'm not going to get into college, I'm never going to get a job—that's what goes on in my head.

Aaron: And that's part of the breakdown?

Participant #06: Yeah and then I'm just freaking out and I'm crying and then... for a good hour and then I'm back to doing my homework.

Aaron: So the typical time frame is about an hour?

Participant #06: Yeah, but now it's a lot longer. It's a two-day process.

Aaron: Why is that?

Participant #06: Because I just have so much anxiety.

Aaron: So the anxiety seems like it's getting worse then?

Participant #06: Yeah but I think it's other things too. I'm just not good at dealing with stress. Before it was reading related and school related. It's still school related but now I just don't have the ability to deal with stress and that's how everything piles up.

Additionally, the inability to succeed at tests on

information known to the DVI student becomes tremendously

frustrating. Test anxiety results which further impairs test performance in a downward spiral.

That's what gets me frustrated. I can't test. On multiple choice tests there's always two answers that sound kind of right and I always choose the wrong one. It's very frustrating. If all my labs are great and I get 100% on all of those, I wish that my grade was based on all the labs. It's really frustrating when your test grade doesn't reflect your knowledge in the class. You don't feel like you are getting the grade you deserve which adds to all the other frustration you had before and makes everything even worse.

Finally, significant stress and lowered self-esteem result from the fact that others, e.g., teachers and parents, want a level of performance that the DVI person cannot achieve. The result is a significant feeling of discouragement.

*Physical frustration.*

DVI causes physical suffering primarily through fatigued eye muscles, eye strain, frequent headaches, light sensitivity, and low energy from using so much to visually process. Vision therapy itself frequently causes additional fatigue and eye strain, especially in the beginning of treatment. Another form of treatment is surgery, which the participants unanimously opposed. One who had it as a child expressed her feelings about it:

My parents took me in to have eye surgery when I was six or so years old. It was very scary and traumatic. I try never to think about it. I cannot go to hospitals anymore. I have been to see the doctor

voluntarily one time since childhood. Nobody made me do the eye exercises, and I suspect that either the surgery wasn't done right, or my vision wasn't corrected because I still can't see very well even though the surgery made both of my eyes point forward. One of them used to turn in way too much.

As described in Chapter II, physical struggling and suffering result from having DVI due to the inability to visually process. To the individual with DVI, the suffering can be both obvious and subtle.

I get tired from my condition. I mean, I cannot tell you every way that the DVI affects me. It affects me in a lot of ways, ways I probably barely notice. But I notice the fatigue and suffer from overstim. Overstim means over-stimulation. When I go to a large area, like a large store, I have to use every part of my vision. Depth perception, distance seeing, looking at things up close, peripheral vision. You name it. And after a short while I feel overwhelmed and exhausted. I just feel really bothered and I want very badly to leave. Maybe others feel this too, but I think that I feel it more often and quicker.

*Participation/reading impairment.*

Because of fatigue and visual processing problems, DVI individuals often suffer impaired reading. "I always struggled in school," said one participant, "reading, I always wanted to be a reader. I could never sustain reading for very long, 20 minutes, 30 minutes tops." Another participant said "it was very frustrating to just read this and not get anything from it and just get disappointing grades back and not understand anything."

Reading difficulties are stressful beyond the task of actually reading a given piece of information at a given moment. Reading is frequently perceived as a gateway to success and high status:

The vision was nobody knew about it and I certainly didn't focus on it. Was it a factor? I think it was a factor. The best indicator of academic prowess and success is reading. That's the best way to get what you are going to get is through reading.

With reading and writing difficulties, the student suffers from a lack of ability to communicate in ways other than verbal.

There was a conflict between the part of me that wanted to talk and interact versus the part that was self-conscious and afraid to speak about reading material or read out loud in front of others. I couldn't participate and that's what helps me learn. Being bored in class just makes you want to learn even less. There is also a conflict between what people want from me and what I can do. It's discouraging. I feel like I have to catch up to all the kids who have been good readers during the early years when I struggled. They know all of these vocabulary words and can write in a way that I just cannot.

Individuals with DVI frequently express anxiety about participating in class sessions. One of the most common concerns was reading out loud in front of a class:

I was afraid to read out loud because I wasn't a very good reader and I would kind of stutter on words and it was difficult for me. I read a lot slower than everyone else; even now I'm still a little nervous about it. I say the wrong words all the time. Orally I know a given word, but I don't know it when I read it. So, before getting diagnosed and treated, I was very

quiet which also probably affected the fun of it for me and could have also attributed to me not enjoying the class just because I wasn't able to be vocal and I wasn't able to make jokes and have fun in class.

*Boredom and confinement.*

In addition to performance difficulties, the DVI student's physical exhaustion and inability to maintain his or her attention on assigned work combine with mandatory and compulsory nature of modern education, e.g., K-12 school, to produce strong feelings of being bored/disinterested. "It doesn't help to be bored in class," said one teenage participant, "that makes you just want to learn even less." To the idea of watching the classroom clock tick by out of boredom, she said "oh my gosh, yes, it's horrible." This was echoed by another participant who added:

I wasn't aware of the vision. All I knew was I needed to move and I needed to go. And what was happening was extremely boring and deadening to me. It was anathema to me. Play was my deal. I think the vision was related to but secondary to the ADD and just imbedded in my whole experience. To be contained hurt a little bit. Oh it was deadly. It was modeled right from the beginning. I could get around my parents but I couldn't get around my teachers because they had me right there under their scrutiny. And under their supervision. There wasn't anything to do in class there wasn't shit to do, just look at the clock which never turned.

Another participant explained that every day in school was a significant challenge because of the boredom and

frustration. Note the emotional tone of this participant's experience. His experience of DVI affected him in physical and emotional ways that influenced his self-concept.

This is what I used to go through: I would get tired, then paying attention to anything was a struggle. It was like walking uphill in quicksand. I experienced this as like, powering down or losing the power to be effective. I wasn't aware that something specific was going wrong with my vision. I just experienced it as global, it was my whole world; it was me. I proceeded from a paradigm where this was normal. So it was who I thought I was.

Another type of frustration results from the stress caused by not being able to be who you want to be. For example, one participant said she felt conflict because she is very verbal, and yet her inability to complete preparatory reading before a given class session left her self-conscious and afraid to talk.

I was very quiet. That also probably affected the fun of it for me and that could have also attributed to me not enjoying the class just because I wasn't able to be vocal and I wasn't able to make jokes and have fun in class. I was too afraid of me saying the wrong thing because I had no idea what the reading was.

*Loss of options and goals.*

Another kind of suffering comes from the loss associated with being unable to follow your dreams and ambitions. For example, one participant longed to be a professional tennis player, but could not hit the ball

because of her DVI. Another longed to be an air force pilot, and was unable to pass the necessary vision tests.

*Social problems.*

Social difficulties emerge as a result of DVI. For children, these can stem from failure to make essential eye-contact, failure to succeed or participate in athletic activities, and from shyness or low self-esteem, e.g., self-consciousness due to having a lazy eye. In adulthood, DVI continues to affect socializing:

I don't think I identify with people or make the same kind of friends with people because I don't have the vision or the memory that goes with what most people have. I can remember going to a ball game two years ago with my son. A customer took us which was nice down to see the Tigers. I couldn't tell you what we talked about, I couldn't tell you what the conversations were because I did everything I could to struggle and just physically observe the game and have a conversation with them.

The DVI itself can have a negative impact on one's self-confidence and sociability. "It contributed to my personality in high school which I'm sure was less socially outgoing than I wanted to be so it held me back." The DVI person may at an early age feel different and isolated from other people.

From the time I was little I knew I was not like everybody else and sometimes I feel like I'm just here, kind of just a guinea pig. I feel very isolated even though I know there are a lot of us with DVI and I had surrounded myself with these people.

The defensive adaptations a person with DVI makes to protect him or herself have lasting impact.

Since I couldn't live up to their rules, I... built a huge wall of anger to authority. It was great because nobody could ever get through it. The wall became a social problem because it affected my developing relationships with my peers, and it hindered my romantic relationships later on. With one woman, I would use the wall, the jokes and stuff, to deflect discussions with some little smart ass comment because I didn't want to deal with it.

It is valuable to note here the description of how social issues transferred to the realm of character and personality, which have direct connection to another issue that will be covered later: Identity and DVI.

Continued criticism from teachers can lead the DVI person to behaviorally live down to social expectations.

When you don't perform according to the cookie cutters, to the culture around you, then you go through a process of being assigned certain deviant characteristics. And those are based on what you don't do and who you are not...there is also a tendency that if you are going to get assigned a degraded position, then you say screw it, I'll act in a degraded way.

Further social problems are caused by impaired athletic performance. Peer criticism, ridicule, and rejection frequently follow. Another kind of suffering comes from impaired athletic performance which become a significant source of stress and low self-esteem. A male participant indicated that:



Playing baseball to me was a nightmare as an outfielder because I couldn't tell how high the ball was or where it was going to come down. I don't have binocular vision. I rely on the backgrounds that show me where things are...against a blue sky, a blue background, there is no way to compare where the baseball is. I couldn't tell where the baseball was going to come down; another embarrassing experience, I think.

A female participant said:

There were these couple of very popular girls and they were the queen bees of the class. I was just a leave me alone and let me survive kind of person. They would have me up against a wall screaming in my face. It was emotional abuse and verbal abuse beyond belief and it was on a regular basis. At the time, I understood this assault to be because I couldn't be relied on to help the team win. I was the one who missed the ball, moved out of the way. I was a perfect kid to be picked on and persecuted.

Others seem to pull ahead in terms of accomplishment while the DVI person seem to fall behind. Something constricts the person, a pinch is felt, but the source is nebulous, vague, and uncertain; an invisible cage around him or herself. The frustration, headaches, fatigue, and stress are constant, chronic companions.

At around the middle school age of development, the DVI individual may become significantly, socially self-conscious. For example, in the area of dating and the opposite sex:

When I entered my young teen years it occurred to me that dating a girl and being cross-eyed and kissing a girl and being cross-eyed and her discovering I was

cross-eyed was a disaster. I was very, very concerned about that because I figured I would be a social outcast. Then I found out the first time I kissed a girl she closed her eyes so it didn't make any difference. Nevertheless it's something that really bothered me and I'm sure had a social affect on me. I was shy around girls because I was afraid of their reaction to my crossed eye...

*Believing I am Not Smart (Fundamentally Flawed)*

The struggles and challenges that go with having DVI tend to eventually be adopted as part's of self. That is, they become one's identity. As a result, the person's experience and adaptations with DVI occur at the characterological level.

"What everybody who has these problems, and it could be a hearing problem or a visual problem, you build your character around getting through and over those hurdles. You go through that obstacle course and jump those hurdles and you become who you are. You know what it affects everything; whether it's romantic or friends or anything, it doesn't matter. The way you act with your pet dog or goldfish whatever. I don't care what anybody says. It changes the person. You know you can't add salt to a recipe, stir it in and take that salt back out. It's in there it's done. Your brain is a pot of stew; once it's in there it's in there.

The DVI person tends to look to experts and authority figures in his environment for insight and comprehension of what is wrong. This occurs even as these experts employ criticism, correction, and external attempts to control and motivate. However, frequently nobody has any idea that DVI exists.

I felt invisible because I reasoned that everyone saw me struggle but figured that I look fine so I'll be fine. I was a girl and nobody worried about girls. I got the feeling because some of the the boys were going through the same thing as me with the school work problems. They got all of this attention and here I sit and can't get it and nobody's really willing to help me.

The criticism received for failure to perform assures the individual with DVI that his struggles are noticed and his failings real. The failure of anyone or anything to enhance success then triggers feelings of being helpless, unworthy of assistance, and unhelpable. The help that is given is in the form of external directives and control.

People were always telling me what to do, like they knew what my problem was. "You don't study enough, stop watching TV, play less video games, do more flash cards." I was the one who always had to have more teacher-parent meetings, more tutors, and more frequent tutoring sessions. I had to take Ritalin because I didn't focus enough. I felt like there was something really wrong with me because of all the feedback that I got that I was never living up to standards. I saw myself as the source of the problem. What was wrong with me was an inherent part of my person. It was never ending, and I felt a kind of queazy terror at the thought that I could fall behind and have to repeat a grade. I just felt like there was no psychic ground underneath me...like I was falling down a hole.

Instructors, tutors, and others give the DVI individual common tricks, tips, tactics that work for regular students: e.g., the use of day planners, highlighters, increased note taking and study from those notes. These do

not work; the DVI individual does not experience increased success, performance, or outcomes.

It became a serious problem because I was failing the class. Then I really had to figure out something to do. So people said use highlighters, write notes, do all this stuff. Nothing was really working very well. I wouldn't absorb information in the class either even from the notes. I'd try to study my notes, do highlighting and all of that and I couldn't do well on the tests and I was doing pretty bad.

Help doesn't seem to help at all. In fact, the DVI student can start to feel significantly worse.

Teachers tried to give me solutions like using a day planner, and they would say try this, the day planner worked for me so it should work for you. I said that it didn't work for me because the coping strategy doesn't work. That is another trap. This kind of help frustrated me.

All of these attempts to help the DVI individual leading to failure to explain and remediate the problem. The individual thus forms conclusions about the self. If there is no outside or readily available reason for conflict and struggling, the DVI individual frequently creates a logical, rational answer: The problem is that the person him or herself is fundamentally flawed, damaged, and of low-worth.

In one school the vice principle was supposed to help me but he never showed up. So I thought that it must be me; I thought that it must be me; I must be stupid. I literally thought that.

I thought I was an idiot when in fact I wasn't.

A sense of guilt builds as others seem to sacrifice their time and money to help the DVI individual, who cannot ever seem to do better no matter how hard he or she tries.

I stopped going to my tutor because as much as I did what she said and worked with her, nothing improved. I just said forget it because it's not helping me anyways. I felt invisible. I also felt guilty that people were spending money on me and I still couldn't succeed. Their help made me feel guilty and embarrassed. So I pushed everybody away. It was my self-worth that was really suffering here.

Lack of proper diagnosis is a common experience for many with DVI, who may have seen numerous specialists. Many of the participants saw optometrists and ophthalmologists, sometimes for years, who never detected the DVI even after the participant reported visual anomalies and struggles.

Participant: So I've always had trouble for the last 20 years not being able to see as well as everybody says I can. So at least 20 years maybe longer that I will go to the eye doctor and have my vision checked and whether I was wearing contacts or glasses, I've worn glasses since I was about six. She would always say you're seeing 20/20 and I would say that I wasn't because that's kind of blurry.

Another participant said:

I saw at least 3 different optometrists in my 20s alone, I probably saw 5-6 total over the course of my life. None of them ever caught anything. I'll never forget the last one I saw before I got my true diagnosis of DVI. This expert looked me in the eyes and said, "my tests show you have a slight astigmatism, which is a very mild double-image caused by the shape of your eye." He sold me some glasses and sent me on my way. That little encounter cost me another 7 years before I got properly diagnosed.

Misdiagnoses of DVI is common, often as Attention-Deficit/ Hyperactivity Disorder (ADHD), or insinuations or outright accusations of laziness. Even when a vision impairment is suspected, getting the proper diagnosis can be extremely difficult. Frequently, an individual will get a multitude of different diagnoses.

Over the course of four years, I saw a number of specialists starting with going back to the original doctor who gave me the diagnosis for glasses. I went to a neuro-ophthalmologist. I went through a little batter of tests, short of an MRI. They were trying to determine if I had a brain tumor or something like that. I had seen another doctor who said I was just a Type A overachiever personality, and that I was just stressed out and should relax. I went to an eye surgeon in Michigan and he wanted to cut. Everybody had a completely different opinion.

Alternatively, authoritative others may seem to ignore the person's struggles. The DVI person receives little attention or assistance. He or she can start to feel unworthy and unimportant.

Since nobody else could help me, I decided that maybe I was supposed to do it myself. I always pushed help away. Nothing I did by myself ever worked. At that point I became invisible because teachers would say they didn't know how to help me.

Teachers and parents implore the DVI individual to explain what is wrong, but he or she has neither the awareness of the origin of the problem nor the vocabulary needed to express it.

The DVI student starts to feel backed into a corner; trapped. There are no right answers. He or she is directed not to give excuses for poor academic outcomes, so he or she may simply own up to it. But this is frequently an unacceptable answer. Clearly, the DVI individual is confronted with the need to adapt to the mounting challenges.

*The trouble with help.*

The DVI person has likely been given experienced many forms of help over the course of childhood and adolescence. However, for many people with DVI, help is more a four letter word than a symbol of being assisted in a way that feels good. Simply put, individuals with DVI frequently experience help as frustrating, and really, as no help at all.

One of the first kinds of help given to DVI students is encouragement to continue giving strong effort. Teachers and others will say to the DVI person that he or she is so intelligent that success will come easily with effort. For the DVI person, however, there is often a sense of lacking the intelligence necessary to be academically successful. What this means is that the DVI person has experienced

mainly feedback that proves a lack of intelligence, e.g., low grades.

Participant: I didn't know what they were talking about, actually. If you say to someone you have real potential, and they've never had real success in the classroom or academically there was no place for it to dock. So I thought it was really tied in with my behavior, I suppose. That I could behave better than I did. But they were really telling me I was smart, and but I had no way of knowing that. I thought I was smart, but not academically.

Aaron: What would you have considered to be a sign of academic success?

Participant: Good grades.

Aaron: Define good grades.

Participant: As and Bs.

For the DVI person, "reality" is that he or she is not smart, and the idea of being really smart can be inconceivable. What that means is that he or she cannot conceive of being smart, and therefor rather than be motivated and inspired by teacher's claims, is actually baffled at best, or shamed and humiliated at worst. The shame and humiliation stem from being told that, essentially, they have once again failed to succeed; this time at using their intelligence to better their success. This only seems like more proof that they are faulty, damaged, lazy, and disinterested in their own success.



The idea of a smart-self is logically false, despite the typical presence of a knowing that he or she is actually bright. The person resolves this conflict by defining the kind of smart he or she is as the non-academic variety. Frequently, the DVI person will feel uncomfortable about the idea of being smart, and feel fraudulent about accepting such praise.

In many cases, DVI individuals become adverse to being helped, and would pull back from, and actively resist, help.

I stopped going to my tutor because as much as I did what she said and worked with her, nothing improved. I just said forget it because it's not helping me anyways. I felt invisible. I also felt guilty that people were spending money on me and I still couldn't succeed. Their help made me feel guilty and embarrassed. So I pushed everybody away. It was my self-worth that was really suffering here.

Help also often exposed the DVI individual to scrutiny, criticism, and perceived rejection. The need for help can be seen as proof that the person is damaged, and thus may exacerbate frustration and a wish to be "perfect" because zero mistakes equals zero corrections or criticism of one's performance; of one's self.

*Avoiding being weak.*

Individuals expressed a preference to struggle alone rather than allow themselves to be perceived as weak. In fact, they regularly concealed the extent of their struggles even though this meant no help would come.

I hate the idea of people thinking of me as weak, incapable or as a lesser person. As a child, I would do everything I could to be daring. It was like, if I could try something then I would. I didn't want the eye doctors to know if I was having a hard time with the tests. I tried to cheat all the tests and never let anyone know how hard a time I had with anything. I also didn't want to be undignified and whine. You know, whine in a little kid's voice, "oooh, I have overstim. I can't see!" I would rather struggle without people looking down on me!

There is a tension that exists between the DVI individual's need for help and need for competence and emotional safety. Individuals with DVI frequently extolled their ability to conceal the extent of their struggles, but complained that nobody could detect how badly they were struggling and provide them with help, even though help often made them feel badly about themselves. This all describes the presence of an inner conflict due to diametrically opposed needs. The DVI person, therefore, is in a constant wrestling match with him or herself; always trying to meet all of his or her needs simultaneously, but being unable to do so because of the nature of the conflict.

*Protectiveness.*

In the statements of those with DVI is a subtle but important quality: protectiveness. While they announce their valor and strength with aplomb, those with DVI frequently describe a sense of fear or vulnerability, especially at the physical level of protecting their sight.

Aaron: You were saying that you were protective of your eyes.

Participant: I am. I can remember in chemistry or whenever you would have to wear those goggles that I was always glad that I have something there that is a barrier in every day life. Stuff isn't going to spatter up on your eyes. Or snowflakes falling...nothing bothers them because you have those glasses there. I like that at this point in my life and I like them to be protected. I think I also might perceive them to be my weakest point. of my whole physical body or self.

While the protectiveness is usually described at a physical level, i.e., protecting one's eyesight, it represents a tone of protectiveness that operates as a kind of theme in their experience. The protectiveness has the feel of an adaptation designed to produce safety and reduce suffering, e.g., avoiding sports in order to protect against being hit in the face or the eyes, and to avoid the embarrassment that attends poor performance.

While appearing bold, those with DVI seem to operate out of an awareness of vulnerability. The vulnerability may

not represent any more vulnerability than normal for any person, yet the missteps and struggles of the self are repetitiously proven to those with DVI. Perhaps this occurs to the point where they are more keenly aware than those without DVI of the variety of ways life can cause pain.

The physical, social, and academic difficulties overlap into the realm of the DVI person's self. It is here that DVI transforms from vision impairment into psychological phenomenon. It is here that DVI begins to work negatively on self-esteem and sense of self. The individual can come to the point of mixing the experience of having DVI with his or her identity.

#### *Struggling to Adapt*

As a result of the DVI experience, the undiagnosed individual adapts in order to compensate for perceptual problems and protect the self from pain.

The first adaptation people experience is the unconscious attempts by the brain to adjust to a world that is not being correctly visually processed.

I never realized that I had a depth perception problem. ...People adapt to it—that's what your brain does. Your brain will help you to adapt like a child that's reaching up in the crib doesn't know the distance between this and the object, but you learn there is space in between you and the object. So the child learns as the adult learns that space when you drive; if you didn't you couldn't drive a car. So you

do adapt. Your brain helps you to overcome a disability.

The next adaptation most people consciously try is to hide the struggles and resulting emotional stress caused by DVI.

Aaron: You were able to evade that which you were not interested in?

Participant: So, by doing that you never are going to act like its a problem for you. You do the trades kind of thing. That's an adult person looking back and saying that. So yeah, I'm not going to be complaining about my eyes to them. For one thing I hated going to the eye doctor: I had to go once a year. And I didn't want to be perceived as having an impairment or a problem.

Aaron: What would have happened do you think if you had been perceived that way?

Participant: I don't know. I don't think anything really.

Aaron: That's the thing, its in the way back.

Participant: I would have been a whiner.

The DVI person is trying to conceal his or her stress and suffering. Above all, this is to hide from others any sign that the person with DVI is less capable or deficient.

Concealment may go beyond omission and silence all the way to active attempts to deceive others. The DVI person encounters many tests in life, and recognizes that if those tests are failed then more frustration and suffering is likely to occur. So, the DVI person learns to trick or

cheat tests and assessments in order to appear normal and avoid humiliation.

Participant: I didn't get my driver's license till I was 33. And part of it I didn't desire the driver's license and part of it was I was afraid I couldn't pass the parking part. And in fact I didn't, I ran over every cone (laughs).

Aaron: You ran over every cone!?

Participant: Yeah the guy said I've never seen anybody do that.

Aaron: And you passed!?

Participant: I didn't pass that one. Then the next one the guy retired and that was really creepy. Then the next one I did was a young guy and I took it in a convertible so I could have 360 degree vision.

Aaron: Ohhhh!

Participant: I just drove up in a convertible, acted nonchalant, it was a nice day, it was a convertible, that helped me seeing.

Aaron: It sounds like there has been the idea of tests and having to pass them in some fashion and cheating them, or fooling people or keeping your cool seems to be.

Participant: Yes, yes yup, uh-huh, yeah.

Aaron: Tell me about that.

Participant: 'cause there's an internal knowing of me that my eyes don't do and function the way other peoples' do quite the same. Nobody can know that except when called upon in these few tests or things. And then I have this big like ominous thing that how can I cheat this.

This same participant described the myriad ways in which she was able to fool vision tests as well. Many of the participants described with pride their ability to get around *the system*. They prided themselves on their ability to improvise and overcome testing and assessment that their vision impairment would have caused them to do poorly or fail at. However, when they cannot succeed or circumvent, an intense frustration bordering on rage fills them. It is a pure anger and there is a madness in their eyes that speaks of deeply felt resentment.

Continued struggling leads to demotivation, and the discovery of another kind of adaptation: Surrender. Why try if you can't win?

I used to sit at the kitchen table crying because I couldn't get the math. I couldn't stand it. So in general, I just said forget it, I'm done trying to explain this to anyone, I'm done trying to get help.

Objectively, surrender might be a less than helpful form of adaptation, but not all adaptations are purely helpful. Some sacrifice a thing like adaptation in return for the emotional release of saying the equivalent of "to hell with everyone's demands and my never-ending frustration, I opt out!" Doing so gives an important kind of emotional release.

Defensive adaptations are built to protect the vulnerable psyche from the critical assault of others.

Defenses such as the wall in the following example, illustrate this form of adaptation.

But the wall did some other things as well. The wall made me feel very comfortable. The wall made it so I didn't have to worry because I took it with me everywhere and protected myself with it. I also did my best to see others as my audience rather than as my foes.

The wall metaphor can be expanded as the concept of creating protection from behind which the DVI person can use another adaptation: Proving his or her worth through exceptional levels of performance.

The wall was based on being the entertainer on stage and the other side of the wall could be the edge of the stage. It was also a way for me to prove to everybody that I was not the idiot. I was not dumb. I was not stupid, because I could fire back a one-liner that was clever and perfectly timed to stun the teacher and make everyone laugh. It was how I was proving myself. I was showing everybody that not only could I do what they were doing, I could do what that guy was doing and that guy and that guy.

In this case, the 43 year old participant recalled building this wall when he was in the third grade. Such is the longevity of adaptations.

In another adaptation, the individual seems to split his or her conscious recognition of the presence of suffering. This split yielded a contradiction: Participants



frequently described numerous instances of suffering, e.g., social isolation, lack of confidence, or impaired school success coupled with intense frustration, and in the same interview, reported that DVI had not been significant enough to truly harm them or keep them from succeeding. This contradiction represented a kind of split. On the one hand, the person was aware of frustrations, difficulties, and limits, but on the other hand maintained a positive overall belief about self-capability, strength, and low-vulnerability. This finding matches previous studies showing that the ability to divide self-concept into specific realms like academic self-concept allows an individual to maintain an overall healthy and functional self-concept.

An additional adaptation is for the flustered DVI student to pursue calm rather than get upset. This is born out of an effort to adjust one's relationship to stressful problems since the DVI problems themselves are frequently unfixable.

If you can't change the facts, it's like there's a little saying, you can't change the direction of the wind but you can change the set of the sail. You can change your reaction to the wind. You can change your reaction to the facts. You can change your reaction to life.

Since parents and teachers are upset, they have a tendency to react to the student's calm by trying to arouse emotional response. Now a battle can come to be between teacher and student: The student perceives his calmness and unflappability as a strength; a sign of personal control and the development of maturity. With it comes a reduction in feeling overwhelmed and out of control. The teacher may perceive this as a threat.

I look back and realize that I got so tired of always trying and failing and then feeling bad, or giving up and not trying and failing and feeling bad, that I came to the realization that there is no control over feeling bad. It is useless, so I just started to move on. You can only be upset about the same thing over and over for so long. eventually, after years, you just don't get that worked up about it, and your appearing calm just makes them so mad at you.

*False self.*

Even as success comes, the lowered self-concept causes the success to be an aberration. The result is a sense of being false and fake should one identify with the success and own it as a merit of the self. Since the self is defined as flawed, failure fits that self-image, where as success seems to the DVI person to be an aberration of their norm. All people create what they believe will be an acceptable public self. In the case of DVI individuals, the

public self, while an adaptation designed to create a socially acceptable face, can feel fraudulent and fake.

I'm above average person in every way. Not quite but some of this personality thing is a made up thing. My natural personality is rather introverted... I have made it a big point in my life since leaving home from Michigan State to be outgoing, optimistic, and pleasant and at times be comical even though some of it is absolutely a total charade like this perfection business. They know it's a scam but they enjoy it.

The DVI individual frequently discounts his or her successes, and makes inferences about his or her successes are too easy or insignificant, while others' successes are indicative of personal power, and the presence of a nearly incomprehensible skill: The ability to easily do nearly impossible tasks, e.g., reading long books.

The DVI student begins to focus on developing his or her own sense of identity, autonomy and locus of control. This is another kind of adaptation. Since other people's solutions do not work for the DVI person, the DVI person will create and use his own. Sometimes these adaptations are to use aspects of the DVI to help productivity. For example, the pressure to perform which causes the DVI individual stress can also stimulate the focus of attention.

One of my adaptations was to get up against a deadline. When I got up against a deadline then I could become more intense. it helped to focus my mind.

When I didn't have a deadline the experience of doing things was not pleasant for me.

As stated earlier, the individual with DVI may eschew help and assistance to avoid guilt and embarrassment.

Individuals may then come to value doing things in his or her own way. A high degree of strength in this self-construct can be a significant protective factor to one's self-esteem.

Resilience becomes prized: I am not a quitter, I can handle anything, I never back down, I never quit, I succeed, I get what I want. The desire to accomplish goals selected and pursued according to one's unique and intrinsic motivation makes those with DVI particularly adept at accomplishing difficult or daunting tasks:

I loved horseback riding, fell all the time. God I've fell so many times it's ridiculous. There was a lot of fear. I guess it was like persistence towards mastery, not giving up. I don't think I ever felt like I made it to mastery but I didn't give up I kept trying.

There is a driven quality that appears. At the same time, there is a palpable quality of being hardened, like someone who has been on the run for so long that his or her resolve and vigilance have hardened. Following diagnosis, the desire to protect self-esteem became crystalized and visible for one participant:

Participant: I'm not one to use the victim word.

Aaron: Why not use the victim word?

Participant: Because I think you deflate your ability to succeed. If you're the victim, then you're the puppet of other people's interest in controlling your behavior. I'm not willing to decide that because I have a vision impairment or I'm short or whatever, that I'm not going to have things that I want or need or whatever. Let's pretend for a minute that I didn't have the vision problem. What would I be doing? If you're not a victim then what could you be doing? I'm trying to do what I would be doing otherwise. ...I don't want you to paint me in a way that I feel like I was victimized. Am I upset, frustrated or am I mad that it occurred? Hell yeah. But that's not a reason to get up in the morning and crawl under the bed.

The bulk of those with DVI are fighters. They do not want sympathy or pity. What they want instead is recognition of their willingness to fight and persevere. Nothing stops them, as they will tell you, and their pride is palpable. They frequently love a challenge because it is an opportunity to display their fearless prowess:

Participant: Spitefulness

Aaron: Spitefulness?

Participant: Yeah just a little. It's like you think I can't hit that? I'll prove it! Even though its on a conscious level I always wanted to compete or do what other people did or other kids. And try myself, try to see if I could. I guess I never had any perception that I couldn't do or read a certain thing.

Aaron: That's interesting, it sounds like there is a certain amount of daring involved.

Participant: It sounds like there kind of is in some ways. Or rising to a challenge.

*Perseverance.*

The use of perseverance is a major adaptation for those with DVI. The idea of taking challenge as a given and pushing through unavoidable barriers is a common notion. "If it's a curse and you recognize that life has got its struggles, then you might as well face it and deal with it. I refuse to give in." This kind of perseverance has a quality of acceptance of *that which is* coupled with a determination to take the source of the difficulty head on. At an unconscious level, such as exists before diagnosis, the DVI person may be aware only that he or she constantly takes general challenges head on. "I just think that I've always challenged myself and made the hurdles necessary. I never realized that this [DVI] was as big of a hurdle as it was." Once a diagnosis makes clear the existence of a vision impairment, the DVI person can focus in on the DVI specifically, e.g., entering challenging academic classes or programs with the advanced knowledge that the DVI will be an obstacle, but one that can be overcome.

Another adaptation is an insatiable desire to succeed in arenas of value to the person. And, in fact, there is a common element to all of those with DVI, the desire for perfection. Perfection seems to offer a form of protection,

or perhaps it is the lack of perfection that creates an emotional vulnerability.

Aaron: Are you a perfectionist?

Participant: Yes. I hate that about me.

Aaron: Sounds like it brings you some kind of suffering if you hate that about yourself.

Participant: Yes. I have to be perfect.

Aaron: If you're not perfect, what happens?

Participant: Oh I'm the one just like when I was a kid who couldn't be trusted to do things properly and completely and well. And yet I'm not one of those really obvious perfectionists, most people wouldn't know it. People who know me well would know.

DVI individuals frequently speak of perfection as if it is an obtainable goal. Because it is not, the inability to achieve perfection seems to vex those with DVI. It also seems to parallel the DVI experience of having an undiagnosed limitation: The person is always trying to achieve standards and outcomes that are out of his or her reach due to DVI. There is a struggle being reenacted here; one where the person is trying to fight their way through an experience of being unable to succeed, all the while believing that perfection is possible and expected by others, e.g., teachers & parents.

Yet, as the great football coach Vince Lombardi once said, one seeks perfection despite the fact that it is

impossible to attain, but in the process achieve excellence. Frequently, while perfection is not achieved, individuals with DVI seem to have a great skill for achieving their personal goals and higher status, perhaps that is a form of excellence? Goal driven behavior becomes a great strength. Poor performance and frustration can either discourage one from trying further, or become fuel to work diligently and tirelessly toward one's goals.

Well, I think it's [DVI] made me work harder. I own my own business, my own consulting practice. I don't think I would have gotten there if things had come easier to me, or if I had started it I would have quit. They did a disc survey (personality profile ) I've always come out a high D...The high D is that you are demanding of yourself.

Not only does struggling with DVI start to enhance work effort toward intrinsically motivated activities, it can also enhance the overall learning process of one's life:

I think you learn more when you struggle. I think despair and struggles in life are really important. You can't grow without struggle. You must have struggle and I think a visual impairment certainly makes you struggle.

The development of resilience comes with an individualistic way of doing things, and this, in turn, can develop into part of a person's identity. One can come to see one's self as an individual who follows his or her own star:



I had an idea about myself as being special. And you could say what you wanted about me, as I measured myself off against other people I understood somewhere inside that I was smart, that I was okay. So, I turned that into individualism. I called myself an individualist.

Avoiding detection by others as weak, or impaired is avoided at all costs. A double edged sword is discovered: Concealing DVI from others makes detection for treatment much harder. But without the ability to conceal his or her struggles, the individual with DVI can feel vulnerable and afraid.

*Re-Examining My Self-Concept*

All of the participants had received a diagnosis of DVI. DVI affects an individual's identity; there are existential issues when one identifies with DVI symptoms, challenges, and difficulties.

First, there is an existential search for meaning, i.e., what is the purpose or significance of having DVI?

Aaron: Are you aware of any conclusions you've come to about yourself, other people, and/or the world?

Participant: Yes. Have I thought about it? Yes. That's where I say faith. I've turned to my faith to say okay, this is what you gave me. If you believe in God or whatever God you do believe in, and you believe God doesn't make mistakes which is what I teach my kids. If he made you and he didn't make mistakes, then you are the way you're supposed to be.

Another existential struggle comes from wondering about reality relative to DVI. The DVI person can be unsure as to which parts of him or herself are "real." There is a major difference between your knowing of yourself, which may be that you are smart and dedicated and interested in your own success, and the reflection of you coming from teachers, parents, and peers, which can be that you are lazy, dumb, and not interested in trying hard or doing well. After a while, the DVI person identifies with the external feedback.

This leaves a sort of double person inside: the person people tell you are and the person you believe yourself to be. The resulting tension between these two opposed selves seems to really affect the DVI person. A person adds to that any adaptations of self. I speak of the false or socially approved self. The person you try to present as your self in order to be what you think others want you to be, or what anyone objectively "should" be. In this way, there can be three kinds of self within the DVI person. The bottom line is that part of having DVI is an experience of identity conflict. It can leave the DVI person feeling like a fake and a fraud, and moreover, unsure which self is the

real self. I think this leads to social discomfort, self-blame, and lowered self-esteem.

After diagnosis, exploration and reframing of the self occurs in relationship to the DVI. DVI related identity issues are directly affected by this process. To begin with, individual reactions to and conclusions about DVI vary after diagnosis. Some individuals see DVI as a mostly benign condition which caused few problems:

It wasn't too big of a deal when I found out. I just thought it was interesting.

Others see it as a significant impairment:

There is a feeling of relief when you finally realize and accept there is a reason for so many misunderstandings. Things are changing. My whole being is changing. it's not that I was stupid.

some as a neutral event:

My Developmental Vision Impairment has been with me from the start. I have always had it and it has always been a part of my life. I don't get overly upset about it because it just is how it is. I accept it.

Whatever the assigned meaning and significance, there is a common experience of relief. It is as if a great struggle against an invisible, suffocating opponent has ended. The result is a sense of freedom and release.

The physical, emotional, and academic symptoms caused by DVI are only part of the inner struggle of having it.

What the individual with DVI also struggles with prior to

diagnosis is the tension created between his unconscious awareness that he or she is afflicted in some unidentifiable, unspeakable, and unknowable way, and the conscious awareness which is blinded from seeing the source.

My [art]work represented, in part, my struggles with DVI.

More than anything, I want to be free; no boundaries, no limitations. The DVI caused limitations that I was only unconsciously aware of. In a way, one of the limitations was that I had this chronic problem, but couldn't ever solve it because it was outside of my awareness. Part of the freedom I sought was to bring the unconscious to my conscious awareness. There is a huge release that comes just from moving a problem from unconscious to conscious. That is what drove me in my paintings and that is what drives me to explore in my life.

Unfortunately, despite how much one figures out about the impact, significance, and implications of DVI on one's life, uncertainty tends to remain.

Now you can go back in time and question well gee I wonder about this or that or that there were certain things that your life was affected by not having normal vision. How do you ever know?

The DVI individual wonders about what may have been affected by DVI and the absence of normal vision. The mystery of having an undetectable primary problem with detectable and unavoidable secondary symptoms is replaced with the mystery of what the full impact of the problem has

been. What has it affected?, e.g., personality, confidence, self-esteem, opportunities, and social encounters.

It is hard to distinguish the effects of DVI with all the other factors that figure into my developmental life. The problem I had in relation to vision comes from textbook reading. While initially I read very fast, I was having trouble perceiving that I was reading. The last part of the word seemed to come before the first. I had trouble comprehending what I was reading, and as a result, I came to the conclusion that I was a dumb kid.

Because DVI is not widely known, accepting the diagnosis seems difficult for those afflicted. They do not know if it is a "real affliction." In other words, is it a made up problem? And does vision therapy actually do anything to help? Is vision therapy a "real solution?" Doubt creeps in, frequently in the form of wondering how DVI could be real if experts such as teachers or pediatricians have not previously detected or even heard of it.

It's hard to tell...do I really have a problem or is it something I can kind of fix at home? Do I need to focus more, am I not doing enough just in general [studying and homework] or is it actually something wrong with my eyes or something going on in my head. There is a lot of doubt.

It is understandable that DVI might be overlooked by an unformed health or education expert. The question must be begged, however, as to why individuals with DVI seem so universally unaware of their visual struggles prior to diagnosis?

DVI occurs at a sensory-perception level so basic that it is difficult to perceive it as anything other than a base-line reality. There is no other experience of vision one can compare it to. The symptoms are easily confused with general fatigue, normal headaches and so forth.

Without any other experience of vision beside their own to compare it to, DVI individuals initially must take it on faith that they have a real problem. And as one participant put it, a contrasting real world experience is essential for the conscious mind to apprehend and comprehend having DVI.

The DVI individual begins a process of reflection and reframing of his or her life and struggles that bolsters, reorganizes and improves self-concept.

When I found out I had DVI ...all of a sudden I had to rethink about the way I had looked at myself for every time I hadn't done an assignment, finished a book, or thought to myself that oh man, this book is gonna be a bitch to read. There were a lot of work habits and rationalizations I had made because of not being able to see properly that still had to be undone and reworked.

Before the process occurs, the individual saw him or herself in a negative light.

Afterwards, there is a new and accurate explanation for the cause of one's struggles: It was not that I was bad or worthless, It was that I could not see properly!

I'm not good at that (athletic activity) and then it starts getting to the social situations. I just find it fascinating now when I look back at all that stuff and realize that's why, I couldn't see.

The result of self-exploration and reframing is a deep felt relief.

Now I can talk to you about my problems because my life finally making sense. It's finally making sense why God put me on this earth. There is direction and meaning and purpose in my life.

On one side is the modern, current person who has reframed his or her self-concept into a more positive one. The other is the ancient, ingrained, negative self-concept that continues to intrude into the person's life constantly. Tension can be detected between the new, more positive self-concept, and the ancient, frequently negative self-concept, which continues to exist and intrude into daily living.

#### *Coming to Terms With DVI*

As the process of reframing the self in light of a DVI diagnosis, regrets and wishes rise to the surface of consciousness.

Aaron: I'm hearing frustration in your voice.

Participant: Absolutely. I think in looking back and learning what I've learned—the piano, my studies, my work, remembering people and faces. If this could have impacted that, how could it not have? Even if it wouldn't have made me where I might dream about being in terms of success.

Between you, me, and the wall posts of whoever you send this to, I have a huge amount of frustration.

The regrets are often centered on lost opportunities and memories of past frustrations. The wishes focus on hope for the future, especially for the futures of children with DVI. "How much different my life could have been is what I would love to give as a gift to somebody else to help a parent or a child not have this."

The recognition of an existing identity and personal mission to help others with DVI frequently accompany the wishes and regrets:

I very frequently feel like I'm somebody from a whole different civilization who's here trying to sort it out and work it through. My other role is to find these other people who find themselves here and wonder, "What is the world and how did I get dumped here?," and help them find themselves and help them be okay.

As a result, old self-defeating messages can be reframed, and a protective field is created that reframes and repels new damage to the self:

I can finally get to a point where I can just go, "that was a bitch"; "that was a shitty moment" instead of it going, "oh my God look they hate me, I'm no good at anything."

In-between the regrets and wishes can be heard a tone of bitter-sweet emotion, relief and fatigue, and satisfaction and sorrow.



There were like all these layers of lack of worth and fault. It all came from my experiences which were affected by a developmental difficulty, DVI, between me and my world because I couldn't see things properly and judge things properly that would cause all of these other things to happen. It was a really big "a-ha!" to make the connection that my role in school is to protect kids and be their advocate because nobody had done it for me. I always knew I was doing it but I just never consciously put the two together.

Another participant echoed these sentiments:

Participant: As we have become more knowledgeable about the mind and the body and the relationship between the two, and psychology. And we now have opportunities to understand things that can correct problems of behavior that just didn't exist in the past

Aaron: ...supposing that in the beginning...

Participant: Supposing that even now, but supposing then, that someone knew that I had astigmatism, that I couldn't see quite the same as other people, and then they actually knew that I had ambliopia. Then they actually knew that I had ambliopia. and then they said we have a program to retrain your brain so that ambliopia had gone away and I had had a success of the mind, and then I might have been in a position where someone said you don't have to be the way you are, that you can be different, then I could have known what the hell they were talking about.

Aaron: And what would that have meant to you?

Participant: Then I would have had an opening, one experience of going from where I was to where someone thought I could be. A success.

Aaron: You seem excited about that even as you are telling me right now.

Participant: Oh yes, well I'm excited about what that means for someone these days when we have the

abilities to diagnose and treat someone that we never had before. We could change people's lives.

Aaron: So it could have changed your life?

Participant: Yes, it could have changed my life I presume for the better.

There does not seem to be an ideal resolution to the participants' tales. The realization of the existence and meaning of DVI and the freedom of the self and release of stress that result are the emotional high points. They are not, however, the end of the story. There is no instant, effortless cure that leads to normalcy, for those with DVI. The participants carry on their physical battles with DVI long after receiving their diagnosis and treatment. Many continue to struggle with issues related to self-esteem, academic and work success, and to rebuild their confidence. Yet, the emotional high points are of such value that they are worth obtaining. To understand the experience of DVI one need only consider the nature of having DVI. This is presented in the following section.

#### *Narrative Synthesis*

The experience of having DVI begins with having no conscious awareness of having DVI. At a young age, you face significant struggles at school; you are unable to succeed at school AND unable to leave. As many problems as

you have, you truly do not want to face the experience of yourself as limited, troubled, broken or otherwise undesirable! You will do whatever you can to avoid detection by others and the low status that accompany it!

The DVI causes academic, emotional, & physical suffering. It is also like the person is stuck in a trap; a no-win situation. He or she is told to improve but can't no matter how hard he or she tries. This fills the person with anger, and frustration, and resentment, and worry, and dread. He or she becomes his or her own task master: constantly lashing, whipping, and berating the self for being bad, vulnerable, and helpless. Eventually, the person often comes to believe that perfection is the only acceptable outcome. Many conflicts arise: wanting compassion from others but being unable to be compassionate to the self, wanting others to help, but doing everything possible to conceal one's suffering, and wanting to be perfect despite the impossibility of becoming so. Perfection becomes a synonym for securing the self by avoiding any reproach and punishment. Emotional overreaction is common when the DVI person cannot overcome or escape perceived criticism or situations likely to bring

perceived criticism, e.g., the assignment of a large reading project.

The inability to comprehend the primary origin of one's struggles and resulting emotional pain leads to confusion and frustration. The DVI person experiences an unconscious feeling of being trapped and limited. He or she can have many emotional and behavioral reactions to this experience, but pushed by the needs of the self and others to assign cause and meaning, the DVI person is likely to conclude that he or she is unintelligent; fundamentally flawed, deficient, and incapable. Acting out of this false, impaired sense of self, the DVI individual encounters social stress due to the need to pretend to be more capable than he or she really believes his or herself to be. This leads to developing a socially approved self, one that frequently appears capable and confident. At the same time, living through this second false-self can make the person feel like a fraud, especially when receiving compliments. The individual struggles to avoid the pain and embarrassment of being given help that does not lead to significantly more successful academic and social outcomes. Engrossed in a paradigm underpinned on frustration and grief, the individual struggles to adapt. Adaptations are

frequently designed to protect and enhance the emotional well-being of the individual. The person with DVI frequently develops perseverance, a strongly developed individuality, and self-reliance. Before diagnosis, the DVI individual is likely to identify with his or her struggles, i.e., he or she tends to believe that chronic struggles and lack of self-efficacy are his or her self or identity.

Following diagnosis, the individual with DVI engages in the activity of re-examining his or her self-concept. A reframing occurs at this point during which the person revisits his or her personal history. Problems and struggles of the past and present are reframed from flaws of a deficient self to problems caused by a vision impairment. The person dis-identifies with his or her struggles and often feels great relief of suffering due to the movement of DVI struggles from unconscious to conscious awareness. Before diagnosis, and sometimes after, DVI is not seen by the sufferer as a problem. It just is as it is. He or she often does not want to make a big deal out of it. In fact, he or she frequently downplays it. One can still see well enough to get by, so he or she focuses on getting by, e.g. academically and socially.

In the end, the individual comes to terms with having DVI, which frequently includes acknowledging regrets about the toll that DVI took on the person's life, accomplishments, and self-esteem. He or she will resolve many aspects of having DVI, but many more, including the presence of lingering negative beliefs about the self, fears of being fraudulent, deficient, and punished, often remain. The false deficient self, the false social self, and the person's actual, authentic self still exist. They can re-emerge to wreak havoc on the person's experience when he or she is emotionally or situationally triggered, which can leave the person with DVI feeling like he or she is still haunted by an inescapable suffering and torment. In addition, the person with DVI frequently espouses and acts on altruistic wishes to spare others from the suffering caused by DVI.

#### *Creative Synthesis*

The experience of having DVI is about more than having a sensory or academic disability. It is about struggling against a force that you cannot consciously conceive of and therefore cannot fight. That single aspect may be the most telling, descriptive, yet difficult to apprehend of all the

aspects experiencing DVI. The following story vividly illustrates this point.

I was thinking about the experience of having DVI, and what I realized about it after I was diagnosed. A metaphor came immediately and clearly to my mind. I once went to a birthday party when I was around 12 years old. It was a sleepover and I had the misfortune to fall asleep first. I was laying on a couch. I remember being so tired that I couldn't keep my eyes open at all, and so I was having one of those sleeps in which you are exhausted. At some point I started to rouse myself to consciousness, but I couldn't fully wake up. I woke up just enough to realize that something was wrong. My eyes remained closed the entire time. I struggled to move my body so I could get up and finish waking up. I felt contained and constrained, and literally became aware that I couldn't move my legs apart enough to get up. In my darkened world of eyes-closed on the couch, I began to struggle. I pulled my legs up and down against each other, scissored them, did anything and everything I could. Nothing worked.

I don't know how long it went on in minutes. Could have been 1 or 5 or 25. I remember trying everything to free myself, but nothing worked. I was confused, I couldn't understand what was wrong with me. I couldn't understand why I was trapped. I just wanted out of it so badly. I alternated between frustration, anger, fear, horror, and the desire to give up. I fell back asleep but woke up to the sensation again several times. I can recall the sense of defeat I felt once I arrived at the conclusion that all of my struggling was useless: My legs simply did not come apart any more.

I was truly in hell. My universe was tiny, dark and closed in all around me. I felt terror creep up in my heart. Eventually, after a seemingly eternal struggle, I awoke fully and opened my eyes. In 2-3 seconds I figured out what was going on, one of my friends had tied his belt around my ankles. That was it. I leaned forward and undid it to gain my freedom. After doing

so, I realized a sensation of such relief that I can't express it in words.

Before I awoke, I had felt doomed; it was as if I had been told I had an incurable and unpronounceable disease. After I awoke, I felt as if someone had told me that I was healthy after all. I was not going to die or be expunged. I felt like I had gotten away from a terrible, horrible trap. This was my experience of struggling with DVI. I was released from a chronic, fear-inducing, nightmarish existence and into the wide-open freedom that I had always dreamed of but lost hope I would ever find.

### *Summary*

The purpose of this chapter is to describe how the primary researcher handled and analyzed the data, and report the findings derived from this study. The final chapter explores the implications and applications of the data gained from this study.



## CHAPTER VI

*Discussion and Conclusions*

The purpose of this chapter is to summarize the implications, applications and limitations of the data gained from this study. Personal and professional ramifications are reflected on and findings are compared with prior research. In addition, limitations of the research is discussed and further studies of value are suggested. Finally, the use and benefit of findings are explored and the primary researcher reflects on the meaning of the research to him.

*Summary of What I Have Done and Learned: Meaning of the Research*

What I have done in this study is write what I believe to be the first qualitative study on the topic of DVI. I have contributed my time and energy to push understanding and knowledge in this area forward. I am quite proud of the achievement, and both hope and believe that the content of this study will move the field of DVI and LD forward both in terms of clinical application and future research. I have also confronted one of my greatest fears: the idea of taking on a long-term academic task and daring to achieve something that only a completely dedicated student could.

In the process, I have learned through actual experience that I have evolved far beyond my beginnings as an LD student who could not read by the end of first grade. Along the way, I have developed many skills: organization, researching, writing, reading, and communication. Because of what I have learned, I feel differently about myself; I have gained deeper insight into my own history and present as one with DVI. I feel more compassion toward myself. As the great Jimi Hendrix once sang, "I used my spirit to smash my mirrors and now the whole world is here for me to see" (Room Full of Mirrors, 1969).

*Implications, Applications and Limitations*

The findings from this study are both useful and beneficial to those with DVI. These findings illuminate and normalize common patterns and variations of the DVI experience. The findings are of use to psychologists, educators, parents, optometrists, vision therapists, and psychotherapists.

In a recent conversation, I discussed the implications of this study with a developmental optometrist. In his own words, the optometrist is always looking for new information to help him make appropriate referrals for multidisciplinary treatment. He knows that he can treat the

optometric aspects of DVI, but has no ability to treat psychological and social aspects. He indicates that the majority of his clients have multiple problems in addition to DVI including poor self-esteem, frustration, anger, negative self-concept and negative social experience. The findings of this study can be of special use in designing treatment models for students with DVI. Specifically, a multi-disciplinary treatment approach can be designed based on the knowledge gained from this study. However, the results have implications for informing the treatment of DVI for all individuals regardless of age.

The proposed treatment model is a multi-disciplinary quarterbacking approach. In this approach, the child is screened by a vision specialist who can detect DVI, assessed for psychological needs and given proper consultation and treatment, while contact is made with educators to explain both the child's optometric DVI needs and limitations, and the presence of and best way to deal with attendant psychological issues such as anxiety, depression, or oppositional defiance. Whatever the configuration of professionals and disciplines treating the child, feedback is given to the child's primary environment: parents and teachers. The objective is to help

the environment begin to adjust to the reality of the child's experience with DVI.

The need to promote better adjustment and resolve conflict is obvious. DVI affects a person deeply, creating stress, fear, fatigue, and confusion. It also seems difficult for the afflicted individual to identify the presence of impaired vision because the symptoms begin at the level of perception. Therefore, any visual experience or difficulty is interpreted as the norm rather than as a problem. Due to lack of general public awareness of DVI's existence or symptoms, it is rare for a person to receive effective clinical diagnosis or treatment. DVI, therefore, is a problem that affects the person significantly with little obvious resources for help available. Any condition with those parameters represents a considerable challenge, and any information that helps meet that challenge is valuable. Hence, the findings of this study have value.

However, for those who experience DVI as problematic, the clinical treatment implication is that time must be taken to assess each DVI person's challenges, suffering, and adaptations on an individual basis. The notion here is that before any treatment is engaged in, a process of exploration and contact with the individual is needed to

determine what problems DVI has caused. From that understanding, the next step is to determine what kinds of help the person needs and what kinds he or she will not accept. It is also vital to be aware that the person with DVI may be highly help-averse. That is, help may have become behaviorally conditioned as a form of demeaning punishment. Clinically, it is vital to keep awareness of the fact that *resistance to help* functions as an adaptation.

For the psychotherapist who treats an individual with DVI, it is critical to understand that the individual's self-esteem depends on partitioning off academic self-esteem from global-self-concept. In a situation like that, a psychotherapist's insistence that the client admit to the "reality" of being helpless or disabled could devastate the client by defeating a key defense mechanism. It may, therefore, be most efficacious to send a DVI individual with low self-esteem to a clinician who works in a warm, nurturing style that accepts the client's viewpoint.

In the field of education, information from this study could inform school and medical personnel of the qualities and experiences of an individual with DVI. This could help increase the frequency referrals for assessment by proper

professionals and resulting accurate diagnosis that lead to more efficacious treatment. At the end of the day, this could contribute to increased student motivation and academic success.

In the field of optometry, information from this study can help optometrists see the whole person and the scope of his or her problems in order to make referrals to psychologists, psychiatrists and educators, and secure better treatment modalities for their clients.

The end result of such collaboration between these four fields can be significant. With the presence of increased interaction, diagnosis and treatment of individuals with DVI could be profoundly increased. Tens of thousands of more children could be aided to avoid the kinds of negative outcomes associated with doing poorly in school, socially and psychologically. These avoidable outcomes include drug abuse, relationship and employment instability, crime and even repeating these patterns with DVI individual's children. In a way, since DVI is hereditary and some of its outcomes negative, it is possible to look at this kind of difficulty as repeating itself in a generational cycle. Interrupting this cycle could yield great improvements for multiple generations.

In addition to the avoidance of negative outcomes, the study of individuals with DVI showed that struggling with DVI can promote resilience; a quality that leads to perseverance and success. DVI students tend to develop significant psychological tools and adaptations. Creativity and problem solving skills become essential and the DVI person is likely to evolve a tremendous reliance on doing things in an authentic, personally satisfying manner.

Learning about the psychological experience of individuals with DVI contributes to a greater understanding of how personal strength, choice making and integrity are developed. From there, it is possible to learn about how to help DVI individuals develop their strengths and avoid negative outcomes.

Another use for the findings of this study is toward helping improve the accessibility of vision therapy. DVI individuals expressed having a hard time fully investing themselves in treatment. This can occur for a number of reasons: The first is that the person may have learned to fear and avoid help because it rarely provided help and frequently resulted in more criticism and an amplified sense of being a dysfunctional person. The second reason is that the person is highly skeptical about whether DVI and

its symptoms are real, and whether or not the treatment is real.

Treatment modalities that accommodate these two reasons are likely to be more effective methods of treatment. They will allow the participant to access help with less doubt and doubt-related tension, thus helping the person decrease stress and increase intrinsic motivation; two qualities associated with enhanced learning process and outcomes. Effective solutions may begin with the clinician simply acknowledging the reality and commonality of these fears out loud to the client. Another possible solution is to develop and utilize conceptual frameworks and pre-designed systematic induction activities. Doing so could help the DVI person have the kind of concrete experience with DVI and its treatment that would enhance said treatment.

DVI students seem tremendously motivated, frequently working hard to achieve goals and show a tendency toward intrinsic motivation. On the positive side, this motivation is a dedicated determination to reach one's goals no matter what. On the negative side, it can be an obsessive quest for perfection; a frustrating attempt to prove the self by reaching a level of achievement that almost no one can, and



then holding one's self to that standard regardless of context or circumstance, e.g., illness when testing, mastering new material instantly.

*Comparison of Findings of This Work With Prior Research*

The findings of this study generally support the findings of previous studies on general LD reviewed in Chapter II, e.g., DVI students have the same tendency toward increased anxiety and frustration as students reviewed in earlier, general LD studies. Academic difficulties, resulting stress between teacher and student, and resilience were common to both participants of earlier research and the current study.

This study reveals close ties between resilience and DVI. Specifically, participants in this study show high levels of resilience in the face of chronic academic, physical and emotional suffering. Almost universally, these participants endure and even prosper during challenging times and experiences. They refuse to give up, quit, or surrender, choosing instead to persevere through to achieving advanced educational degrees, financial success, and become positive, contributing members of their communities as teachers (e.g., K-12 and college professors and staff), mental and other health care workers (e.g.,

therapists, social workers, school counselors, disability therapists). The experience of having DVI drives the participants to seek perfection. Not perfection as a concept of doing all work perfectly, rather perfection as a state of being beyond culpability; existing and acting in a way that causes no mistakes or other opportunities for external criticism.

The current study found that peer rejection is similar for the DVI population to that of the general LD population. This study tapped specific feelings of injury, hostility, and resentment suffered by rejected DVI individuals.

It is valuable to note that the quantitative and qualitative methodologies complimented each other for the study of DVI. Where quantitative studies were able to indicate the presence of psychological distress, e.g., anxiety and depression stemming from peer rejection, this qualitative study on DVI was able to add depth of understanding, e.g., the personal, subjective experience of one who has been rejected as a part of having DVI. Together, this qualitative study supports and enhances the results of the quantitative studies. Combined, they create

a comprehensive tapestry of understanding, insight, and information.

When it came to DVI and families, the current study revealed that DVI individuals expressed the perspective that they were on their own when it came to dealing with DVI. This is an extension of the general finding from previous studies that indicated that LD leads to difficulties in the family. In the case of DVI, parents frequently were unable to detect DVI, and where it was discovered did not prove to be of much assistance. This perspective indicates that the experience of DVI affects the family, but then also the family's reaction, including what kind of assistance is offered or available, can in turn have an even larger impact on the DVI person. In other words, the current study indicates that the interaction between DVI and family may be significantly under-appreciated and thus require further investigation.

Both this study and previous studies agree that individuals with DVI-LD experience intense frustration and despair about ongoing academic struggles and the inability to make improvements. Both studies show that there is similar impairment of self-efficacy, self-concept, and self-esteem in both the DVI and general LD populations.

Further, that there are similar attributions of self-as-powerless and others-as-powerful in both populations. In both current and previous studies, self-esteem was found to improve significantly following diagnosis and identification of the source of chronic academic, social, and inter-personal struggles.

The current study found that DVI individuals have such a similar experience to LD students that the term DVI-LD is indeed an accurate and valid label, and that DVI is a learning disability. Each state possesses a list of specific disabilities and challenges that are considered part of their special education domain. When a student is identified as having one of these listed special needs, the student becomes entitled to services and assistance designed to meet those needs. These needs are met in order to promote the development of well equipped members of society, and to fulfill the legal mandate of this country that every child is entitled to the best education possible. A strong case is made by this study and this researcher for the incorporation of DVI on the list of learning disabilities. To do so has the promise of getting valuable assistance to DVI individuals, and promoting greater performance and reduced stress for all involved:

Teacher, student, parents, peers, and the greater community. Including DVI as an official learning disability will raise the condition's profile in the public's awareness. Greater understanding, enhanced opportunity for diagnosis and treatment, and more effective psychological and educational development for the child will result. In return, treated individuals with DVI are more likely to contribute to society and less likely to experience the kind of negative outcomes that harm society: e.g., drug abuse, high unemployment rates, and high rates of juvenile and adult delinquency.

#### *Application of Research Findings*

The process and completion of this study has many personal and professional ramifications. In both areas, I have enhanced my self knowledge. I know the experience of having DVI intimately, and I can speak of it with expertise. Such mastery and comprehension allows me to complete several objectives of both a personal and professional nature.

I commit to writing and publishing a series of articles about the existence of my research, the results I found, and the implications toward both treatment and future research. I envision publishing these articles

simultaneously in education, optometry, and psychology magazines and periodicals. By doing so, I hope to raise awareness of DVI as an issue of significance to all three disciplines, and perhaps initiate further interdisciplinary discussion. My desire is to help raise the awareness of DVI and its attendant issues to the point that many disciplines come together to present recommendations and implications to all who work with or could be of help to those who have DVI.

Following the articles, I commit to writing a book on the experience of being a child with learning disabilities; DVI in particular. I will do this so that there will be, as one participant described it, at least one actual book on the topic of DVI that someone who has just received a diagnosis can utilize. This has implications for treatment as more knowledge upfront may help a newly diagnosed person with DVI invest themselves more fully in treatment.

*Unstoppable: An LD and DVI person's guide to success* is the working title for this manuscript. What follows is a first draft of the introduction:

This project is a book, an authentic guide written in the subjective first person as an encourager to those with learning disabilities. It draws upon my own experience and knowledge, both of myself and with others, about the unique threats that confront LD individuals. From false ideas that lead one to

procrastinate and avoid work to defining the self as a lesser being with limited capabilities, this book shines a light into every dark corner of an LD person's soul. This is also a practical guide that explores the outlooks and perspectives that produce success, courage, integrity and other aspects of most peoples' ideal selves. This is me taking you on a journey where you can see through my eyes and discover new viewpoints that both validate your previous experience and helps you forge the new identity for yourself that you desire in your deepest heart. It draws on the best and most ancient ideas of self-improvement, growth and humanistic self-actualization fields. I cannot be everywhere at once, in a physical sense, but through this book it is my definite hope that my ideas can be.

Finally, I will use my expertise in the area of DVI-LD to create a clinical practice that aids in the diagnosis and treatment through consulting, psychotherapy, and public speaking at schools and conventions. I believe that these contributions will make the best use of my research and be of most service to humanity as a whole.

#### *Limitations of the Study*

Although effective and valuable, this study had four major limitations: 1) The geographical location of the participants, 2) The limited number of participants, 3) The high intelligence of the participants, and 4) the research was conducted under an academic time-frame.

1. Participants in this study were from SE Michigan and their results may not generalize to the entire population of this country or the world.

2. Only 13 participants were used in this study, and while that is sufficient number to satisfy the requirements of the heuristic research model, a larger sample would be required to establish broad applicability of findings.

3. Participants, although not tested for IQ, appear, based on education and verbal communication ability, to have above average intelligence. If this is so, then then they each possessed a characteristic known from previous studies to act as both a protective and vulnerability enhancing factor. That is, based on conclusions from previous studies, the presence of high intelligence seems to offer some protection from emotional suffering, but also increases the likelihood of suffering, e.g. because teachers often treat the bright-but-learning disabled student in an over-controlling, punitive, and hostile ways that produce emotional suffering.

4. This research was conducted under the restraint of a dissertation academic timeframe. The result was that a limited amount of time was available for data analysis, which could result in additional findings having been overlooked, and, therefore, un- or underreported.

*Future Directions of Research in the Area of DVI*



Further study on DVI is required to better understand the experience. Experimental design is indicated to enhance the value of the study of DVI by demonstrating the statistic prevalence of DVI symptoms, and to identify the most effective forms of treatment. It would be valuable to learn what treatment modalities are the most practical, effective, and affordable. In this study, the researcher was able to cover what he set out to: Qualitatively explore the experience of having DVI with a quantitative research methodology.

#### *Summary*

The overall objective for this chapter was to describe the implications and applications of the data. To do so, the researcher described the meaning and value of the study to his personal and professional endeavors, compared the findings and themes of the literature review with his own, indicated to whom and in what ways the results of the study can be of value, explained what the researcher intends to do with the results, and commented on how they can be applied toward clinical practice and further research. This study achieved its research objectives, and in doing added significantly to the body of knowledge that exists about DVI. There now exists the promise of further and more

revealing insight into the needs and limitations of those with DVI. This study has illuminated the previously invisible nature DVI individuals and their experience of having DVI.

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## APPENDIX A

## Instructions to Research Participants

Dear xxxxxxxx,

Thank you for your interest in my research on the experience of having Developmental Vision Impairment. I value the unique contribution that you can make to my study and am excited about the possibility of your participation in it. The purpose of this letter is to reiterate some of the things that we have already discussed and to secure your signature on the attached Participation Release Form.

I will be employing a qualitative research model through which I am seeking comprehensive descriptions of your experience. In this way, I hope to illuminate or answer my question: what is the experience of having developmental vision impairment? Through your participation as a co-researcher, I hope to understand the essence of the phenomenon as it reveals itself in your experience. And from this knowledge, I hope to gain insight into the ways that individuals with similar experiences (children, adults and adolescents), who face similar challenges to yours, can be helped. You will be asked to recall specific episodes

and events in your life in which you experienced the phenomenon under investigation. I am seeing vivid, accurate portrayals of what these experiences were like for you: Your thoughts, feelings, and behaviors; as well as situations, events, places, and people connected with your experience. You may also wish to share records, personal journals or other ways in which you have recorded your experience--for example, in letters, papers, poems or artwork.

The initial phase of your research contribution is to begin to immerse yourself in this process and record your memories, thoughts, and feelings concerning your personal experience of having and growing up with Developmental Vision Impairment. I am interested in knowing how your Developmental Vision Impairment and experiences with Developmental Vision Impairment have affected your relationship with yourself, with others, and with your academic and employment success in life. I would also like to learn what I can about how this experience affects your values, ethics, priorities. In order to assist you, I am enclosing a series of questions that focus on the awareness of the impact of Developmental Vision Impairment on your life. Also enclosed are journal pages for your use in

recording whatever comes into your consciousness regarding this experience. These written notes may be of assistance in your process of comprehensively articulating the constituents and qualities of this experience. Please bring these journal pages and any other personal writings or materials that hold significance for you to our interview session.

If you have any questions, I can be reached at home at (XXX)XXX-XXXX or work (XXX)XXX-XXXX. I deeply appreciate your participation and look forward to our collaboration on this research project.

Sincerely,

Aaron Goldner, M.A., Psy.S., TLLP  
Doctoral Candidate

APPENDIX B

Informed Consent Form

Center For Humanistic Studies Graduate School

Informed Consent for Participants

(2005)

Aaron Goldner, M.A., Psy.S., TLLP

Marjorie Scott

Ph.D.

Principle Investigator

Faculty

Supervisor

PLEASE READ THIS DOCUMENT CAREFULLY, SIGN YOUR NAME BELOW ONLY IF YOU AGREE TO PARTICIPATE AND YOU FULLY UNDERSTAND YOUR RIGHTS. YOUR SIGNATURE IS REQUIRED FOR PARTICIPATION. YOU MUST BE 18 YEARS OF AGE TO PARTICIPATE. IF YOU DESIRE A COPY OF THIS CONSENT FORM, YOU MAY REQUEST ONE AND WE WILL PROVIDE IT.

The policy of the Center For Humanistic Studies Graduate School is that all research participation is voluntary, and you have the right to withdraw at any time, without prejudice, should you object to the nature of the research. Your responses are confidential. Any report of the data



collected will be in summary form, without identifying individuals. You are entitled to ask questions and to receive an explanation after your participation.

If you have concerns about your participation in this study, you may contact:

**Principle Investigator:** Aaron Goldner, M.A., Psy. S., TLLP  
(xxx) xxx-xxxx (cell phone), (xxx) xxx-xxxx (home phone).

**Description of the study:**

This is a 2 session interview where your experience of having Developmental Vision Impairment will be explored.

**Nature of Participation:**

You will participate in two sessions. In the first session you will share your experience of having Developmental Vision Impairment. In the second session, you will have the opportunity to review the work that has been done with your interview.

The first session is expected to take at least an hour and fifteen minutes and no more than an hour and forty minutes.

The interview will be audio recorded and that recording transcribed for purposes of data collection and analysis.

The length of the second session will vary but be up to the discretion of the participant.

**Purpose of the Study:**

The purpose is to explore the subjective experience of having Developmental Vision Impairment. This means we want to discover as much information as possible about the research participant's unique experience, feelings, beliefs, perspectives and understandings. Simply put, there are no right or wrong answers.

**Possible Risks:**

A) Before, during or after the interview you may experience thoughts, feelings or ideas that you find distressing, upsetting or otherwise objectionable. For instance, the memories of past struggles may cause you to think about areas of continuing challenge and difficulty, or feel negative emotional states in regard to past events. Should this occur for you, the primary researcher will make himself available. Should you desire ongoing therapeutic assistance the primary researcher will provide referrals to a licensed psychotherapist.

B) You will be asked to provide confidential information about yourself.

**Possible Benefits:**

A) Before, during or as a result of your participation, you may gain valuable insights into your experience with

Developmental Vision Impairment. For instance, you may develop new perspectives on the strengths you have developed while having the experience of Developmental Vision Impairment.

B) When your participation is complete, you will be given an opportunity to learn about this research, which may be useful to you in understanding yourself and others.

C) Your participation may contribute to new understanding and insight that can be of benefit to others who have shared a similar experience with Developmental Vision Impairment.

D) You will have an opportunity to contribute to psychological science by participating in this research.

**Confidentiality:**

You will be assigned a code number which will protect your identity. All data will be kept in secured files, in accord with the standards of the Center For Humanistic Studies Graduate School, federal regulations, and the American Psychological Association. All identifying information will be removed as soon as your participation is complete. No one will be able to discern which ideas, experiences or beliefs are yours.

**Opportunities to Question:**

Any technical questions about this research may be directed to:

Principle Investigator: Aaron Goldner, M.A., Psy. S., TLLP

Phone: (xxx) xxx-xxxx

Any questions regarding your rights as a research participant or research-related injuries may be directed to: Marjorie Scott, Ph.D., Committee Chair, (xxx) xxx-xxxx, ext. xxx.

**Opportunities to Withdraw at Will:**

If you decide now or at any point to withdraw this consent or stop participating, you are free to do so. You are free to do so at no penalty to yourself. You are free to omit ideas and beliefs and continue participating at no penalty.

**Opportunities to be Informed of Results:**

In all likelihood, the results will be fully available around 10/1/2006. Preliminary results will be available earlier. If you wish to be told the results of this research, please contact Aaron Goldner. He will either meet with you or direct you to where you can read a copy of the results. In addition, there is a chance that the results from this study will be published in a scientific



## APPENDIX C

## General Interview Guide

1. What is your experience of having Developmental Vision Impairment?
2. What was your experience with Developmental Vision Impairment relative to school?
3. What did you tell yourself about your vision impairment?
4. When did you first realize that you had vision impairment?
5. How was your life affected by your DVI?

Specific queries may be directed toward different modes of experiencing--feeling, thinking or bodily sensations; different phases of life or education; as well as in social situations and inter and intrapersonal relationships.

## APPENDIX D

## Verbatim Interview

The purpose of this appendix is to present one verbatim interview so that the reader gains an understanding of my process.

## Interview #8

Aaron: What is your experience of having vision impairment?

Participant: Well up until probably the end of school which was last year, was mostly confusion. As I sum it up in one word, it would be confusion because it was just like for a long time there's only one opinion about it which is either you're lazy or you're AD/HD. The vision impairments come into it and then all of a sudden it was like well you're going to go take this test and it's going to see if you have this vision impairment and then you're going to go to eye therapy which obviously doesn't sound like a real therapy. I'm like there's physical therapy, what's eye therapy and then you go in and put on these goggles and look at the screen and focus on this, and it's not as lifting weights or it doesn't seem like it's the same tactile response that you get because you're not really aware of when your eyes focus and not focus anyway. Well, of course, that's all it was. You weren't lazy or an ADD it was just your eyes. So I'm like what you were telling me for the past 15 years was that not true, it's all of a sudden you have to rethink about the way you've looked every time you haven't done an assignment or when you haven't finished a book or when you thought to yourself when a book comes up and you think to yourself, I'm going to have to read this book. It wasn't that I wasn't thinking it's going to be hard for me to read it was just naturally harder for me to read. It's not like you're thinking to yourself, well my eyes aren't going to focus on this very well, you're thinking to yourself oh man this is gonna be a bitch to read. It seems like it's more subconscious that you don't see it happening and it's like you don't see through anyone else's eyes but your own. So it's not like

you can look and say, wow people are focusing their eyes differently. You look at things differently than everyone else. It's like thinking about someone in an extreme case that has hallucinations and is trying to convince people if they're real when they can only see them. It's like you can't see through my perception and I can't see through yours so my vision I always thought was normal for me. Normal people shouldn't have this hard a time reading so there was nothing odd about that. It must be something different because we all see the same. So me having a hard time reading this book must have to do with something else. The eyes don't even come into it. You don't even think about that. It's like I have ADD and you think that. I can't concentrate on it. It's just too hard. I can't process the information. That kind of thing has nothing to do with my eyes or not focusing right. You think it may have something to do with your brain being miss wired somehow. Not that I thought I was stupid, but I kind of developed this thing where it was like, well there's book learning and then there's intelligence. I just don't do go at book learning. I don't process information from books. It was kind of how I resolved it. So it's just kind of like interesting how that works.

Aaron: Has it resolved the confusion?

Participant: Yeah. People saying to you that you're an intelligent kid, why aren't you getting better grades? And you go, "I am an intelligent kid; Why aren't I getting better grades?" If you keep asking for an answer then you eventually try to make an answer. That answer that pretty much served you for the last 10 years and then all of a sudden its like, "No that wasn't it." And it was just this old simple answer your eyes were wrong. Your eyes were a little bit messed up, go here for a few months; it's all fixed now go and get As. It's kind of like a shock and you don't want to believe it. You don't want to disbelieve what everyone else has been telling you this whole time. It's like you've been on drugs and everyone has said you're ADD and then it's like all of a sudden all of those people were wrong. It doesn't seem that it's possible that many people can be wrong and that many teachers can be wrong.

Aaron: How can everyone be wrong and nobody else catch it?



Participant: And not only that but then you say something like, "I went to eye therapy" and people give you an odd look. So what you're telling me is that there's this one doctor at an eye place who specializes in eye therapy and gets his check from telling people they need eye therapy like they need tonic water or snake oil, saying that you have ADD or you're lazy. Mostly my mom is really adamant about it and because of that I felt like we were getting taken for a ride for a long time. My mom went in and talked about the teachers and it was like what are they going to say when they find out that I'm just really ADD. I was convinced that I was lazy and ADD so it's like even if this eye thing does exist that's not really the problem; that's like having a hangnail when you really have a broken foot. That might be a little part of it but that's not the whole thing. And it wasn't the whole thing but I think it was because there were a lot of work habits and rationalizations I had made because of not being able to see properly that still had to be undone and reworked. It was a definite kind of root of the problem and it wasn't the idea that it was the root of the problem, it was the idea that it was like this little superficial thing that maybe made it a little bit harder. Just like having a lazy eye muscle and having an operation because I have a lazy muscle how that might make things a little bit harder but it doesn't cripple me like ADD. Crippling sounds really hard but crippling as in not being able to get your work done, not being able to concentrate. That's the only thing though but to me I can sit and watch not just like a big flashy TV show that has a lot of things going on, but I can watch the History channel for hours. Because it's real information about facts and history and what's going on. After the first week I might have forgotten about 70% of it because I'm not studying it, it's just kind of like coming in and out. I usually get about 30%, like a whole day of just watching the History channel. So it was like why I can do that when you think of that as being informative and being on the same level as possibly reading a book or getting the same kind of qualitative feedback. Like concrete things, not just watching a cartoon where there are lots of bright flashy things to keep you entertained. The History channel is not really known for bright, flashy things. It was like why can I do that and why can I not read a book about history. I could watch a history channel show about Gandhi and watch this whole thing and get all these really cool facts but I couldn't

read the book about it. The same information I couldn't process on page. I couldn't retain any of it either unless I read it through several times.

Aaron: What was it like for you having that discrepancy where you could gain information from one place and not from another?

Participant: Well it's not rationalization, well the auditories are gone now. I'm not a reader, learner. I guess that's just how my brain works. I guess my eyes are different and I guess that's how my brain works. That's what it kind of like rationalizes for myself. But what I'm saying is about there were other things to undo was after that it was also reinforcement that my grades didn't just immediately shoot up. Now in college I think I'm all As and Bs. I don't think I've ever had that ever. It's partly because it was discovering that you can do things. You can sit down and read a book now; whereas before it was like I just can't do it. Not only you told yourself but there's evidence that you can't do that for the longest time. All of a sudden you rediscover that you can do things that you didn't know you could do or like finding out you have super powers all of a sudden. I can lift 300 pounds? When did that happen? I can run super fast.

Aaron: I'm always hearing I don't know if it's confusion or almost like incredulity like I can do this?

Participant: Yeah. But it's still confusion because it goes from confusion about is this a real eye therapy and is this is a real problem to being, well, it must not be a real problem because I'm still getting bad grades, to being, well, I proved to myself it's not a real thing, but I can do things I obviously couldn't do before. I went through this kind of up and down of it's fake, it's real, we were taken, we weren't taken.

Aaron: It's back and forth and it sounds like it's traveling all around because as soon as you settle on one of the old answers, you get some new outcome like, "Oh my God I read this whole book" which moves everything else out of the water like what would I do if the world was flat today? What would happen to your conception of things?

Participant: I mean you would be like yeah the world's flat, sweet and then go on like well I guess I can't walk to the end of the earth now 'cause I'll fall off. You're still going to be like that's not right on such a fundamental thing about me because it's really how you do your school work pretty much and by the time you get to high school is a fundamental characteristic of who you are. It's like the earth being around you, its fact, and you know it. There was a reason for it and all the conclusions you came up with were false. Now the conclusions the people were telling you were false. It takes a while to kind of re-educate yourself on what you can do and what you can't do. I wouldn't be able to do homework for long periods of time and then it was like I can sit down and do this for an hour? That's crazy. Then, of course, it makes it easier because then it's not like I got trained in timed working for 15 minutes and slacking off for 30 minutes, working for 15 minutes and slacking off for 30 minutes. It's like I can work for an hour and not have to work the rest of the night. It's like learning a new schedule and it took a long time. It's not like you look at a schedule and then re-establish it. It's like it's all kind of internal so it takes longer for you to rehab these little epiphanies along the way and kind of realize it.

Aaron: I'm hearing that you can do like a vision therapy and things will change. But then there's a period of time that goes by before you get different outcomes, so it's not as though you can still be in the moment while everything is different it's like you're kind of having to constantly go backwards, rewinding to catch up.

Participant: And it's not like vision therapy you go through it and it's like wow I see in color now. It's not like this heads up display that you get to see what exactly is different; it's this long gradual process that's like snake oil in that you're still seeing. It's not like you put on glasses and all of a sudden everything becomes clear. Everything is as clear as it ever was, it's just kind of easier and it's harder to see those things. For me it was like specific examples where that popped up and I went, now that must be something different. I went to a camp and had the book *Memoirs of a Geisha* which is a very thick book. When I got the book, I said that I was going to hate reading this. I love books and I love stories but it's like

wow I'm going to really not like having to sit down and read this and it's going to take me forever because I'm going to have to read it 15 minutes at a time. I ended up sitting in my bunk in the cabin and I just read it cover to cover in 3 days which was like wow I can do that. Because I was involved in the story and I wasn't realizing it. There was no kind of part of my brain saying stop you can't do anymore because I was so involved in the story. Then if I'm half way through the book I kind of realize that I'm not just stopping and it was like let's see if I can do  $\frac{3}{4}$  of the book, or maybe I should just finish the book. It was kind like testing these limits again.

Aaron: Before there was no testing of them because they were established.

Participant: You know you tested them your whole life so you set a limit here and then all of a sudden it's like maybe I can move the limit out over here. The limit is like 3 hours now instead of 15 minutes.

Aaron: Is there a little bit of almost like a tentative quality like I had this visual of waiting for the other shoe to drop?

Participant: To me, it was like you're thinking all of a sudden that the words are going to fall off the page and you're not going to be able to read it anymore or it's going to be disheartening. You start thinking that you can do this and all of a sudden if it just falls apart that would be really disheartening. That would be like falling off the wagon somehow.

Aaron: It seems like you would accomplish much but you can't really count on it.

Participant: It doesn't matter, it's still the same. I still have to go back to the tried and true method of 15 minutes, 1/2 hour, 15 minutes, So it wasn't until I completed the book, it was like I completed the book. That's really weird. I think up until that point I had only completed one book and I really enjoyed the book. There was a whole series and I couldn't even complete the rest of the series. I really liked the book. It was the Enders Game book. I was pretty young when I read it but it

was one of these things like even though I loved the first book it was really daunting to think about reading the rest of it. It was like I enjoy the story line of this book but if I read the second one, I'll have to read the third one and I'll have to read the fourth one. Because it gets more like an ongoing story line.

Aaron: What I think I'm hearing you say is that it's like I really like the first one, now if I start reading the second one I'm kind of committing to like reading the rest of these, and am I just setting myself up for a disappointment or....

Participant: right or am I going to get half way into it and it's going to ruin the first one because I won't know the whole story now. It's like I know the whole story of that one book. This is like it's safer just to not read the rest of them and only enjoy reading the first one. It's not like this ambition of if I read all of them and I'll know the whole story. I'm happy with knowing the first one and I don't need to know any of the other ones because I might not finish them and I might get disoriented and the story might not be as impact.

Aaron: You might lose some of the feeling that you got from the first one.

Participant: Right. I was so happy I finished it. If I start going into the rest of them, I'm just going to feel bad that I never finished the rest of them rather than feeling good that I finished the first one. So that's kind of the feeling for me behind it. I don't think I have much more to say on this topic.

Aaron: There's really the one main question. What is your experience of having this vision impairment and I've got a couple of other sub questions that I can draw on now. One is when did you first realize that you had the vision impairment?

Participant: When they told me I did. It was right around when I was going into middle school either the first or second year of middle school. No, no, no. That was around the first or second year of high school.

Aaron: So we're talking about 4 or 5 years ago because you're about 18 now so that was around 14 when you went to high school.

Participant: Yeah probably around then about 4 or 5 years ago. Actually probably around 3 or 4 years ago. But I had no clue. It wasn't even like it was brought up beforehand so there wasn't like well there's thing called vision therapy and you might have an eye disorder; it was like go into this place, they tell you you have vision therapy and that's the first time you've ever heard of it. It's not like someone saying that there's this thing called cancer and people get it and it's this real big problem and it's your blood turning against itself and then it's like well you have it but at that point in time you understand what it is and how it works, so you're not surprised you have cancer and it's not like a disbelief that there's a thing called cancer. Where if you went to this optometrist and you have this crazy vision problem. You'd have to pay us a bunch of money and we'll fix it for you. But it's not just for glasses. I have to look at little pictures with minor differences and put on crazy different colored eye goggles and all this kind of stuff. That will determine it. It's like yeah, okay.

Aaron: You've never seen or heard of anything like this, not only the condition but the process that you went through.

Participant: When you think about it they give you these red goggles you put on and it just seems like this is something you would order out of the back of a comic book; it does seem like a professional, any doctor-study therapy thing; it doesn't seem like real.

Aaron: It sounds a little hokey or is it a little like—where's the big machine that goes beep. What are you talking about I'm flipping lenses and I'm looking at pictures.

Participant: I don't want to separate from when you're going in to get your eyes tested because of something blurry because it's like they put a lens in front, it's still blurry, they put a lens in front, it's still blurry, they put a lens in front, it's clear, cool. I see the problem. This is like you put something red up, it looks

like a picture, you put something blue up, it looks like a picture, you put them both ways, and it still looks like a picture.

Aaron: And then the person across from you is saying I can see you have this vision problem.

Participant: It's a lot of trust on whoever there is telling you but when everyone else has told you something the complete opposite or not even mention that this is real, then it's like I'm trusting you versus everyone else whose ever told me anything about the way I'm still having problems. Eventually, things started making more sense when they were saying this was only compounded by my lazy eye problem, that it seemed more like a process. It seemed like there was more of a history to the reason I had it. That I probably had it a little bit but because of what I knew was real problem, I had a real lazy eye muscle. I can see how that can affect the way I see. So it's like oh so  $A+B=C$ ; it's not just like C is there and there's no A and there's no B.

Aaron: So it sounds like it almost has to be all of these pieces to look at it once to really assemble it. You can look at a piece and later go of course this was always part of this whole scenario. I had problems doing this with my vision; I had problems doing that with my vision, now I don't have those problems.

Participant: Eventually I did come to kind of understand that as I started testing my boundaries and all of a sudden it was like I realized that I could do things I couldn't do before and there must be a reason for that. I knew part of it was me getting older and you get a larger attention span and things like that, but I'm sure that when you get older all of a sudden it's not like you can just read a book all the way through where the year before you couldn't. I don't think that's it. And I don't think that all of a sudden the people that weren't readers in middle school when they hit maturity all of a sudden its like "sweet I can read one piece" and all of a sudden it just comes to them. It seems more like the people that were readers stayed readers and the people that didn't like books stayed not liking books. I always liked the idea of books. I liked reading synopsis. I didn't like all the old classics because I never wanted to read them but I liked knowing what they

were about, and I liked going to see plot points and I liked knowing what was the arc of the book and what happens like the fairy-tail version of it.

Aaron: In other words you never liked to know the story and you liked to know about it, but again you couldn't access it through 300 pages of 8 point type.

Participant: If you ever talked to my mother, and I don't think she ever put this together, but she'll always say my sister, my father and my mother were all readers, my sister and my mother especially--anything they will pick up and read it. I would get books and it would be really depressing because it would have to be a real specific book to really get me to want to read it so it would be like the Jackie Chan autobiography; of course you'd want to read that. So I'd be working real hard and be half way through it and my sister would say, "Yeah I found it last night and I read it." It's like thanks. This was my book and I was going to read this one.

Aaron: So what was it like being the different person, the one that everyone is reading all these books all the time?

Participant: It was kind of like I'm not a reader, I'm not that person. My mom kept on saying, "You like stories and you like when I read your books, but you don't like reading books." And almost as if I should have an answer. You're right, I guess I don't read. That's the only real answer that's there. So that's why I kind of think I gravitated towards movies, video games and things like that is that there are still stories in those but I don't have to read text. Even though people like my parents who are real readers are like, "Well they didn't include everything in the book." I get the main points in the story, I get what happens, I can talk about the book, I can discuss the book with other people and I understand what's going on. All of my teachers always thought I was well read. They always thought that I had read tons of books and that was because I would listen to what my parents said, it would be like, "Wow that's a great story." I would retain it and I would say so in the invisible man where blah, blah, blah, blah happened, any person would have assumed that I read the book. I had never picked up a copy of that book in my life. It was just that I liked the story so much and I'm sure that if I could read it I would really enjoy it, but I



didn't read because it was so hard to read. And my mom I don't think ever figured this out. She would always be like, "Well everyone thinks you read a lot and you don't." Then I kind of eventually felt like I was cheating because folks are so hard to read and I'm taking the credit when I didn't do all the hard work. Books aren't hard work. I always thought these are like scholarly people who read because that's such a hard thing to do. They must be dedicated, consecrated, nose to the grindstone people to get through books whereas it's like War and Peace or like a really long and dry book. For even a teen novel people don't read them because it's work, people read them because it's fun. It was so much work and I just figured it all sounded like me or processed like me that it must be incredibly hard for them too, so they must have more conviction and love books and stories more than me and they must love stories more than me and they must....

Aaron: Sounds like judgments about yourself relative to other people. Whose got the scholarly qualities and you don't.

Participant: Right. And that's kind of the whole perception thing is I couldn't see that it wasn't hard for them. I think that really affected us—that you can't see what you want to see; and even if you could you would have to sit in their eyes for a long time and read through a whole book and then realize you've read the whole book without it being hard. It's like amorphous kind of thing to think about, it's not concrete.

Aaron: So in what you're saying I'm hearing that because it's so hard for you and you believe there's no difference between how you see and other people see, that at that point you naturally describe this incredible ability to other people. But you do this thing that you know you're a smart guy; everyone says you're a smart guy, yet they have this obdurate level that they can go to.

Participant: It's like. "Well they must be a good basketball player or they must be a good dancer, I just don't have any rhythm. It's like this intrinsic thing that I'm missing and eventually it's like well I guess I'm not that. So then to think this wasn't a piece I was missing. It was just a perception problem I had. It was not that I was missing an arm which is like what it seems

like. Well I'm just missing the reading arm so I can't read. I'm missing an essential organ to how I process things.

Aaron: Yeah, you've been doing this for so long you hadn't realized that with some particular training you could begin to articulate your arm and yourself.

Participant: It's like the difference to that one of the easiest ways especially when you're younger to deal with it, is telling yourself you're not going to be that thin. It's like you tried really, really hard and everyone wonders why you can't do it and not in the way that really means why can't you read, you should be able to read. Because I was a good reader when I read tests and I was always super high on reading. It kind of reinforces the idea that I'm just not trying. Well if I can't try or if I'm just not trying and it's too hard for me to try, well then I'm not going to try. I'm just not a reader. I don't do that. I'm a drawer that's what I do. What's the problem with that—I'm a drawer, not a reader. It's like this real defensive thing that it's like you completely divorced yourself from the idea of reading and being a reader. I was a good reader because my test scores show it's like I'm not a reader reader, I'm a reader.

Aaron: Qualifications it almost sounds like. Everything is qualified.

Participant: Right. It doesn't make sense and it didn't make sense then anymore than it makes sense now it's just that you have to come up with something to deal with it because otherwise it's just like why am I doing this. You have to come up with something to make it not totally depressing but even though it's a pretty depressing thought that everyone else says something you don't. It's kind of like be retarded or not retarded. It's not like you're retarded or you're not retarded; I'm a reader or I'm not a reader. It's simple as that—it's a medical thing. It's science; it's biology.

Aaron: Some people can read and other people think difference of adaptation. There's a thing that's come up a couple of times now that I want to check out with you which is the idea of having to come up with something. Having to

come up with an answer, and having to come up with an explanation and so forth.

Participant: It's like why didn't you do your homework, and mainly the answer to those of course is I didn't get it done. But it's always like this other kind of question which is like why can't you do this. You meant to ask that directly—you're such a smart kid but you don't turn in your work,

Aaron: Which implies....?

Participant: Which implies why you can't do this. And it's like why can't I do it. And then what answer do you come up with. You don't come up with my eyes are flawed—you come up with I'm ADD cause everyone says that's a big thing—ADD.

Aaron: When you give that explanation then what do people say?

Participant: I didn't give that explanation. I didn't say I must be ADD. You kind of go, I was busy, or it's too hard. You don't just say you're ADD. I find that's what kind of people answer for themselves, it's either lazy or ADD. The people that say lazy are the same people that would say someone who was really ADD was actually lazy. So it's not like there are two camps; it's ethnic that the people that are already prejudiced against, the idea of people being ADD are the same kind of prejudice. They're like well he must not be ADD, he must be lazy. Well even if he is ADD, it's just another term for lazy.

Aaron: So the question is are you lazy or are you lazy with a BS name that other people may give a crap about.

Participant: Right, I'm just trying to make sure that everyone kind of thinks you're ADD no matter what that means to them or lazy what that means to them. So that was always kind of a conclusion was like he doesn't pay attention, he must be ADD. Even before I went to a doctor and they said I was ADD it was like that was the conclusion. That was always in my mind that I must be ADD and so going to the doctor was like confirming it. It wasn't finding it out; whereas going to the eye therapist was like finding it out. So that was a big difference. That was another thing why it made the eye therapist seeing what's critical was like in addition to what all these

other people were telling me, this doctor said I was ADD. Even though by that point I had stopped taking the ADD medicine, Aderol seemed like pretty heavy ADD medicine, and there were a lot of issues with paranoia and side effects like that so the kind of conclusion my mom came to was it's better to have ADD than be super-like almost to the point of bi-polar about school and about getting things done, and kind of a paranoia as in like I just got assigned this, I know I'm not going to get it done. I'm paranoid and I'm not going to get it done already. A week before it's like I know I can't do this, I know I can't this done. That's kind of like heightened paranoia. It was like it's better for him to be ADD than to have that. So even at the point I stopped taking it it was still the idea that I am ADD it's just that it's better to be ADD than to have this really important medicine. Just like people prefer to die rather than take all the medicine and feel crappy the rest of their lives. It was that kind of thing. It all kind of like contributed to not really believing what it's like if you weren't ADD, you were this. And now I kind of believe it because there are a lot of things I do where I have a long attention span. Honestly I think that it takes an attention span to watch The History channel.

Aaron: That sounds reasonable to me and again it's not like....

Participant: But there were hints to reception that it's like TV so it must not take attention span.

Aaron: Is there a subtle societal thing going on where it's like the way you can get information is too easy, or cheating and or it's not really....

Participant: It's like that's great—you can trivia from TV but you're not getting the facts from books. It's like you sure know a lot of trivia knowledge but you can't reference it to a book. I was always told I have trivia knowledge which I'm sure is true to some extent but it's not like I absorb knowledge. It's that I sit and I watch The History Channel for a long time. It's the same kind of thing when you read a book. It's just that of course I don't get as in depth and consistent information because a half-hour TV show is not the same as reading a book about World War II.

Aaron: No, it probably wouldn't be as much information.

Participant: Right. It's not as consistent. It's like it kind of jumps around but it's still information so it's trivia information the fact that I can't draw a direct line through these concepts, but I still have information and I'm still getting it somehow, I wasn't just absorbing it which is what everyone's kind of perception was like. It was like you can't read to get information but you'll just get it through osmosis.

Aaron: Your accomplishments would be diminished because it didn't require this Herculean effort. It's like a trap. It's like you can't do the huge effort thing therefore you can't have information.

Participant: Well it kind of backed up because you'd think that reading is such a hard thing then people say that watching TV for information isn't really getting information so it kind of reinforces that reading is intact but you just can't do.

Aaron: It's the ultimate. It's the thing you want to be able to do.

Participant: Right. Its high bars like when you can read a book about history, you gotten to the top of the mountain. I really enjoyed history which is one of my favorite subjects. I wouldn't read a book about history even though I enjoyed it. I still don't even want to read a book about science. It's kind of like when I can read that's when I'm not intelligent but I'm smart if there's a good distinction between there. I know things when I can read. I have this general intelligence and this general problem solving thing but when I'm knowledgeable and when I'm well-read is when I can read things. I'm not smart, but I'm intelligent and I know trivia. There's this weird sub category of separation things and now it's not like the knowledge that I have that's a little bit more disjointed from watching television is any less information than the information you get from a book. It's not like it's a different type of information, it's still just facts.

Aaron: In other words, there's not a value difference. When is it better than the other one just by the fact that one is coming in one form and the other one is coming in another form?

Participant: Right. I agree that I didn't get as in depth but I also knew a lot of different things that were more diverse. I would go in to history or English classes or even in general discussion, someone would say something and I would say, "Oh what about blah, blah, blah, blah." They'd say do you know a lot about the way the State's program works. And you don't want to say I watched a TV show on it. That's not the same as I read a book on it.

Aaron: Isn't that the commercial for the best Holiday Inn or something? Some emergency happens and the guy knows all of his emergency information. That's incredible for you doctor. "No I stayed at the Inn last night and they had free cable."

Participant: It was a smart choice to choose that Inn so I'm a smart person now. This is kind of their plight but the same type of thing in the opposite where it's like saying you watch it on TV doesn't carry the same weight and doesn't carry the same kind of respect, like the respect of the information. Well if you saw it on TV it must not—there's a question of whether that's real as opposed to you read it in a book. That must be real where it's like on TV or something it's like they'll say anything on TV, it's that kind of thing.

Aaron: Yeah, TV is fancy make believe. Once it's in print now that's more substantial and it's a lot truer.

Participant: Right. It kind of establishes that whole trivia knowledge thing that it's trivial knowledge it's not as important.

Aaron: I don't know if it's a catch 22, but there's a paradoxical conflict situation I was hearing and I want to check it out with you. You said something about people thought you were well-read but if people really get to know you, like your parents and your family knows you really well, they know it's not true. On the one hand it's nice that people think you're well-read but on the other hand, there's this cheating, fraudulent piece....

Participant: That's what it was that people would say I'm so well-read and it would be yeah.

Aaron: So just having the appearance was actually in some ways uncomfortable. Having the appearance of being learned and knowledgeable.

Participant: And even for people that knew me well but weren't necessarily family like my friends, it was like every z-w-a-t but doesn't read a lot. They knew I didn't read but they knew I had knowledge about books so it was like whatever came up it was kind of like contradiction. If they were going to say something about the way I read it was like, he reads a lot but he doesn't read a lot. This was kind of like what the idea was. It was just really weird. You'd be in a group and would be writing a paper, and they'd be like talk to Ed he's smart. And they'd be like we don't want Ed in the group though because he doesn't read.

Aaron: What if people were soliciting for information with some regard.... Is that social exclusion thing or like people....

Participant: It wasn't social exclusion it was like where do I fit. Am I the one that people come to for information or am I not?

Aaron: You're either a smart kid or a dumb kid. You accomplished it or a lazy kid.

Participant: Right. And I think it was a girl once that actually articulated to me that I was smart, but lazy. It stuck with me like I wonder if that's how people see me. That was the thing. It was like if all of a sudden I'd say, "You have a giant hump, and I'd say, I have a giant hump?" It's like that's how people perceive me and the way I talk in class, and it took a long time to realize that was almost a complement because they were saying that I obviously present myself as very intelligent but I don't get good grades. The only way they could resolve it is that I just naturally know things because I'm lazy.

Aaron: To be able to accomplish things is sort of a behavior action whereas the word "lazy" seems to almost hang more like a judgment like more reflective of something on the inside. Like you are already being lazy by definition.

Participant: This is who you are. You can't change this so if you have blue eyes you are lazy. That's genetics. I'm sorry, there's nothing you can do about it.

Aaron: The notion of identity--What's really true about one's self? You know you're smart but other people may see you this other way. It's like other feedback people give you. Well the teacher is saying ADD; no one else has any other explanation.

Participant: But also you didn't want to show your grades to people not just because you got bad grades but because it's not an indication that I'm not smart. It would be like someone saying well what grades did you get. You might go into this whole long conversation of, "Well see that doesn't really indicate what I learned because I learned a whole bunch." Well, I got a D. Obviously if you got a D that means you're not smart. It was like this whole kind of dance that every time, well it was like you need to get to know me and then you'll understand that I'm intelligent but I just don't get good grades.

Aaron: I made a note that something you said was a dance, is a dance complex? If you're just lazy it's like if you choose to pick up a pen and do something then you would be productive. This isn't that simple. It's like well I got this grade but not only are there always extenuating circumstances, but it is not who I necessarily am. School is a lot about producing work. On one hand you're going to school and spending eight hours a day there producing all of this work but the results are adding up to who you are and, therefore, is there something about that about investing your time doing something that you kind of want to keep hidden and on the down-low?

Participant: Towards high school it kind of falls into this idea that was like for me I am just lazy. I kind of stopped thinking about being ADD consciously, it was always the question that when school started back I'm going to get good grades this year but am I going to get the work done. That's not a question of am I going to be able or am I going to, I have to pass or I just don't. It was kind of like well I just don't get work done. I had this kind of idea that I am lazy and a lot of kids fight grades, even though they did D work they D grades, and I get D grades. I don't turn into the work that's a fact. It stopped being



about whether I could or couldn't do it, whether it was hard for me or not hard for me. The plain fact was I didn't do it and I deserve those grades, that's just the way things are. When I don't get work done, it was like....

Aaron: Like the struggles and the reasons of actually getting left behind and it's your only dwelling in like is it done or not done.

Participant: It doesn't matter how or why it wasn't done. I didn't get it done. The funny thing is that teachers still say why wasn't this done and it's like there's a real paradox with teachers because they're like, "I don't want excuses," but they want to know why you didn't get things done. Anything you say is an excuse. You're not going to say, what else you can say but an excuse. Well that doesn't sound like an excuse. I still don't know what they want you to say. So I always just say I just didn't get it done and they will tell me that's not a very good answer. Well, if I had said anything else, you would say I don't want excuses.

Aaron: It's like a trap. What can you do?

Participant: It's kind of like an emotional trap because you feel bad either way. You feel bad if they don't like your answer; you feel bad if they don't like your answer for another reason. The fact is you didn't get it done.

Aaron: Maybe that's the piece where you like everything else openly you learn. You learn to that everything is relevant other than the bottom line. No one cares about the reasons, no one wants to really hear the reasons, and you don't even understand the reasons, nobody gets the reasons, the reasons don't make any sense. I'm trying to put together some of these ideas you had.

Participant: It's like in elementary school it's this logical thing and I see that now for someone who initially didn't have an eye problem. It's like there must be a logical reason why you're not getting this done and an eye problem is a logical reason. But of course no one sees that. So why didn't you get this done; I don't know. You have to know. I don't know. It kind of comes to the idea that these are trap questions. You hear them so much and you only have the same answer and you're not being

disingenuous and you're not hiding something. It's not like when you break a lamp and your mom says, "What are you doing?" and you say, "Nothing." You know what you did. The only thing you know is that you didn't get it done. You don't know anything else. You don't even really have the skills to articulate that it was hard or harder because I didn't know how easy it was for anyone else. If they think that this isn't a big deal to get this work done, it must not be a big deal so it must not be hard. All these kinds of things ends up just being like trap questions and this is what everyone must have. This is what everyone must have. No one must be able to answer these. I can look back on that now and see how that's now not necessarily a trick question when you're younger because they're really trying to figure out what's wrong. When it seemed like to me they were just trying to berate me. It was almost like someone saying you're stupid. It wasn't like saying we need to figure this out, we need to find out what wrong, it was like because asking me as if I knew, and I don't know why you keep asking me.

Aaron: I'm seeing a big light bulb kind of go off here. They're coming to you for the answers and because the nature of the developmental vision impairment is such that you don't know you got it, you can say, "You know my eyeballs turn pink and Google back and forth."

Participant: See what happens is and even when you say something like it was very leading, do the words jump around on the page and it's like yes and if I don't get my work done they might jump around on the page. It wasn't like yes they do jump around on the page. That seems like that could make sense. It's like well you must be ADD.

Aaron: I was going to say it's not like by telling you you're ADD; well they give you two options, two answers. You're lazy or you're ADD. Which would you prefer? If you think I've got it and every other damn teacher thinks I've got it, then that's what I've got.

Participant: Even though I kind of had a reaction to that, I had a reaction like that's a cop out, I'm not ADD, I just must be lazy and that's a fact of life. I'm lazy. It was like I ain't going to fall for this ADD stuff. It is kind of like which do you choose? Choose one, A or B. In general, it was just really frustrating. Even now that I

think back on those conversations where I'm not sure a lot of times due to my mom because she's really involved and she thinks I'm smart and all of that. It would be like elementary school and middle school. Middle school I remember specifically is like all my teachers got together and we had this big meeting with all the students and they're going, "See I have a planner, I use a planner. That's how I remember to get things done." Because you do come up with excuses so I'd be like why just forget to do it.

Aaron: So they started to slowly take away your excuses.

Participant: Right and it was like if they were coming up with answers, it would be supportive and it would be this big support group. What it felt like it was this big kind of like trial. Putting me on trial, putting all my excuses on trial, putting anything I would have thought on trial. Well you say this, well I do this and this helps me, or you say this and I do this and this helps me. So if you do these things you should improve and I didn't.

Aaron: You mean you'd do them but not improve or you would do them at all?

Participant: Well I'd do them and not improve, then it's like well why use a planner if it doesn't help anyway and it's just a hassle anyway. Now I use a planner and I understand the purpose of it. Of course I'm sure I did forget some of the stuff, but even when I remembered the stuff it didn't help.

Aaron: Well remember to climb Mt. Kilimanjaro using toothpicks rather than advanced mountain climbing but still trying to climb Mt. Kilimanjaro with toothpicks.

Participant: But of course remembering the climate must not have been the problem because when you remembered it, it didn't help you climb it anyway. All these kinds of things are kind of like stacked, layered and interconnected. That was like what my mom was saying when this happened and I was going that must not be true. It can't go this deep; it can't be this thick for something that's like my eyes don't work correctly. That can't be the huge involved kind of issue. It can't be the root upon all of this has happened because you really attributed to it.

That crazy talk—I'm just lazy, I've known this forever. You can't fool me anymore with ADD.

Aaron: Gee that's amazing. You painted a really vivid picture of your experience of being in these rooms, being in these situations and especially this inner experience you're describing of like being on trial. The word came to me like persecution.

Participant: Well I mean it's like I'm sitting there at the desk and there's all my teachers around me and my mother. Even though they're being supportive, the ultimate question is why can't you do it. So it's like I have a planner. If you have a planner, why can't you do it? That's what I remembered specifically but I couldn't remember whatever else you were saying, but it was like I do this. If you do this why can't you still not do it?

Aaron: In other words, well you do this and if you say no, well you need to. Why can you still not do it? If you do it, they'll say he must be lying, or otherwise it would be working if you did. There are no right answers in any of these questions,

Participant: My music teacher his answer was that he used to be kind of crazy and he used to act out. His answers never showed emotion. Everyone had kind of their own coping strategies. So they were like this coping strategy worked for me and it should work for you. I said that it didn't work for me because coping strategy doesn't work. I don't even know what I'm coping with. Am I coping with laziness? How do you cope with laziness especially when it's obviously a genetic thing?

Aaron: I guess I'm not interested in my own success; that's what laziness is—not interested in my own success and I don't have to get up and do anything about it. I am hearing another thing running through here which is like this universality thing. Vision us a universal phenomenon. Everybody sees the same way. Success is a universal phenomenon. Everybody succeeds the same way. There are good ways and there are bad ways.

Participant: Everyone succeeds different ways, but none of the ways everyone else succeeds works for you. So it must be a problem with you. Someone might say, "I succeeded this

way; I succeeded that way." None of these work for you. Why? Why don't they work for you? Because they don't. There's no answer to that. You're not a doctor and in some ways it's the same as if someone can't see the blackboard. It's a pretty obvious kind of thing. But I get tired reading very fast. It's not an easy thing to see. It seems like you're just lazy. It's like I'm so lazy I can't finish this book. Oh well.

Aaron: After you've made an effort and strained yourself you get to the point where no amount of additional effort will help you have a tendency to be lazy. This is what laziness must really be like because I don't even want to try anymore.

Participant: And you kind of settle into it. You're still going to feel bad about it but you're not really going to change it because changing it doesn't really do anything. So feel bad about it for a while, get over it, try to make an excuse or two. I have this mid-term for anatomy which is a huge mid-term and I had to draw these many bones, I'm going to label this and go over and over this. Even now because I've never had to study for something huge after post eye therapy, even now it's still kind of weird for me to study this long. It was like when I took this English test I started realizing after about several months after the eye therapy, it's like you start pushing your boundaries. It's not that you only see clearly and you avoid the things in front of you, it's like you don't see any differently so you just expect you're going to run into things, and you don't think to move them to the side.

Aaron: So for you there's been a real learning process of testing and re-testing and pushing?

Participant: Yes. I've been writing these, my English teacher wants to be a Philosophy teacher, long involved philosophy papers. Before I would write short papers I had a difficult time because you've got to I wrote short papers because after a while of looking at things on the screen even when I was typing, things just got too hard and I would stop. So I would wrap it up in one sentence and paper done. So now it's like I'm writing five page papers and they're not that hard. People say papers are hard but it's different because I thought papers were hard because of the

physical task of writing them, not thinking of what to write which is what people mean when they say papers are hard. They don't know what to write. It was like someone saying a mile is hard to run and it's like yes I know a mile is hard to run. It's not a mile is hard to run because you can't think of where to run; it's like it's hard to run because it's physically hard to run. So the papers weren't hard because I couldn't think of things to write about; it was hard to physically look at a screen for that long and look all over the words and process all of that and kind of focus on it. So it was different to all of a sudden be like I could just put my thoughts down and then go back and revise, and revise again, and revise again. I would revise the paper maybe three times. I would write a draft, I would have the teacher correct the spelling and that would reflect the final. I didn't understand the consequence for doing like the actual contents of the paper because I didn't want to read through all that again to remember what I wrote. Then you'd be forced to read it later and then wonder what did you write. You'd say that isn't what I meant, that isn't what I wanted. This makes no sense. Now I'll go over a paper three times and by the end when I'm reading it over, I'm pretty familiar with what I've written. I pretty much think I've clarified myself. The first paper I wrote for this English class was about a page. It was after the last paper I wrote and then we had the mid-term and I went in and looked at my first paper and I said that was really small. At the time I didn't remember anything that small. It was because I hadn't pushed my boundaries. I just stopped where I would normally stop. Now I'm writing 5 page papers. On Monday I can write a first draft, on Tuesday I can go over to the second draft, on Thursday I can do the third draft, and on Friday I can turn it in and it's a nicely completed paper. Even now I'm still discovering things from situations that I can do that I could do. I was always like writing is hard. The drugs didn't help me write the paper better, and I'm sure that's another reason why I just decided to stop taking them. I could focus in class more.

Aaron: Well you had some magic bullet and it was bringing the world down or whatever it was. It was just peppering you up and making you more active.

Participant: It was making me more focused but I don't think I was anymore unfocused than a normal kid. It's just

as if you hyper focused a normal kid. My teachers say you're more focused but you're still not getting your work done. It's like—that's great, I'm focused, but the work is still not getting done. Why is that?

Aaron: That's that bottom line again.

Participant: I'm just wondering what else is there that I didn't perceive correctly. It's all perception because it's how I thought about how hard reading was when it really isn't that hard. It's how I thought writing was like a physical endurance test when it's really not.

Aaron: If something is hard, it wasn't just because you were struggling, it's because it in and of itself is a great difficulty.

Participant: Right. It's like climbing a mountain. And there are some people that climb mountains and there are some people that can't.

Aaron: So would that like diminish your interest in trying things knowing that something is super hard and you know you already have a problem with those things. Is that what you're going to be spending your time?

Participant: Right. My mother always had this thing kind of like the trail of her son that she'd be like you won't read a book that I recommend, but you will read a book that you choose. At the time, I told her I wasn't interested in the books she was suggested but it wasn't because of the subject matter. When I picked up a book I could see things about it in that I'd think that I could read it. A lot of times I still can read it. There are still tons of books that are on my bookshelf that I've never read. I've read the first paragraph, put it back on my bookshelf and never read again. So when she would say that I never read the books she picked out, I would say that I don't read books at all. The books I pick out that I read have very specific kinds of short chapter, short paragraphs. It doesn't even matter if the plot is twisty turvy; it matters if the writing goes everywhere. If the writing kind of doubled back on itself and goes around and is really flowery in a way that is too hard to follow. I'd have to read that several times before I could figure out what the heck they were talking about. The coping strategy for that is that

you read through it, it's like skipping to the good parts, that you just keep reading the words and you understand what the words mean, but you don't understand what the heck it's talking about until you get inside. So it's almost like scanning but it's not scanning because I wasn't skipping words. I wasn't like when you scan a book and you just try to get the major part out; I was reading every word. It was just that they weren't connecting and I wasn't making an effort because I would have to read the same sentence 3 or 4 times. Even now there are sentences that are hard for me to read, but I can go over them 3, 4 or 5 times, move on and I can still read the rest of the paper or I can read the whole paper like I did before but read it through again. It's not the same—it's not the same. It's not like I have to give up and then come back after I have relaxed. I only know this now because I have to let my eyes relax because they get tired and they need to recoup. It's not really procrastinating but it turns in to procrastinating after a while. It's not like you come back to it with fresh eyes if you just take a five-minute break and still come back to it with really, really tired eyes.

Aaron: You need enough time to actually relax, let the muscles deoxygenate and all that kind of stuff.

Participant: But the thing about that is that it turns in to what do you do in that time. Well, you play video games. Playing video games is far more fun than doing homework. So you do video games instead of homework.

Aaron: It evolves into that; it's not that you don't sit down with a book with the intention to work for a while. You sit down and start working, then bam you can't work anymore. Now what are you going to do? The examples you're giving are people taking your limitations personally. Like the teacher says, "Well I gave you all these suggestions and offered my help, but you won't take it." If you're doing something wrong here.

Participant: Well, I never thought that was a big part of it. Consciously it might happen but it's like you're letting the teacher down. You can't get it done. I taught you and you're letting them down. After a while you kind of get the thing where it's like, Yeah I let people down but you got to deal with it. I let you down. And not in a real aggressive way but just an insane bottom line matter of



fact way where it's like good, bad, why I do it, why I don't do it, I let you down.

Aaron: The why doesn't matter, the fact is the end product is you got let down.

Participant: It was always kind of a thing whenever I didn't turn in an assignment, I stopped worrying about it. It's like worry, worry, worry, an assignment's due; I'm not going to get it down. Stop worrying about that assignment, next one is coming up so start worrying about that one.

Aaron: You can only worry about something for so long before it's time for it to get off the table because the next thing to worry about is coming.

Participant: Exactly. And that's what I didn't get because there were like kids getting As and Bs that were like, "I didn't turn in that paper last week." I thought to myself I didn't turn in a paper last week and I'm not still worrying about it. I've got this new paper to worry about. For them, it was like it's going to have repercussions later which, even though I knew that, it was like the repercussions are coming now that there's a new paper to worry about when they were thinking I'm going to get this new paper done and don't have to worry about it. It was like if I worried about every single paper I didn't turn in there would be far too much to worry about, like I would be a mess. So you just push things off the table.

Aaron: I was going to say, I'm hearing that there is an energy thing as well. You should drain the energy from the task you're trying to read and then from the worrying. After a while, it's like it's the people wanting you to have a reaction, the teachers are trying to get you to be as concerned as they are.

Participant: Exactly. That's a big part of it. Why aren't you concerned about this? Why don't you care about your grades?

Aaron: How do you say you do care but if you care then you'd be getting it done?

Participant: Exactly. I was really getting upset about my grades. My mother was getting distraught about this too. I was really bothered by it. In high school it was like why be bothered by it. It doesn't happen, it doesn't get done. If I get someone to turn it in—sweet. If it doesn't get done, what's the point in worrying about it because I'd just get really upset and it doesn't happen anyway? You kind of get this palace.

Aaron: There's an adaptation that I'm hearing in that too is that how are the little things like a paper not getting turned in really going to rock your world that hard.

Participant: Right. To me it was almost like a sign of maturity. These kids still get angry at a teacher for not turning things in. They can't see that, why can't they see that, because they never had to think of the bottom line as always why. When they didn't turn something in, the why a lot of times triggered the teacher. So but to me the why was always myself. It was always me. Like other kids they turned things in and they get things in on time and it's not as hard for them so when they don't they say I get things in all the time, why didn't I get this one in. Well it must not be it must be teacher. For a long time I knew it was just me, so it was like get angry at the teacher? For what? I didn't turn the work in and I understand it was my fault.

Aaron: I don't know if it's too much responsibility or whatever, but you took responsibility for everything that happened. It wasn't really out of maturity. It was out of necessity. You can do that every once in a while and get a way with it, but if you do it all of the time eventually someone says they didn't do that. So in that way, that's the only way to deal with it. Whereas if you are only doing 20 papers and you don't turn one in, then it's easier to say that this one didn't get done because of a reason that wasn't my fault.

Aaron: That excuse should add explanation....

Participant: It's not there because you can't use it every single time because people call you on it. The teachers call out kids who do that and get good grades, but since they're getting good grades it's like well I get good grades what are you talking about. It's easier to justify

it. I couldn't justify it because I wasn't getting good grades and there must have been a reason.

Aaron: A good point is over time you experienced so many different teachers, students and so many different assignments, what's the commonality for all of them? So is it true that perhaps over time your experience with your vision impairment became more and more concrete proof of something amiss with you or something depicting from you, within you and not happening to you.

Participant: Yeah. I always felt like and I always had this kind of issue even towards the beginning of high school, probably from middle school to high school I felt this thing where it was like I got myself into this mess, I'm the only person who can get myself out of this mess. A teacher is going to give me a break on this assignment or she's going to.... "You're going to get me a tutor? A tutor's not going to help. What are you talking about?", like this is my problem and getting a tutor is like a slap in the face." It's like you keep saying this is my problem and that this is something that's wrong with me. And then you're going to get someone to come in and fix it for me? No I don't think so; I'm going to fix it myself. This is my problem.

Aaron: Is there an ownership or a personal economy thing?

Participant: They can't fix it. It's my personal, internal problem that no tutor's going to be able to fix. At the end of the day I might do my work while they're there but I'm not going to do the work when they leave. It's not going to change. I might stop doing the work when they're there after a while. After a while with the tutoring session it would be like I'm still not getting good grades. This tutor is obviously not helping.

Aaron: Even if you do what they say and get the tutor, then it's like....

Participant: After a while the tutor stops being effective because it's no longer this new thing that might help; it's this old thing that doesn't work. That's what it felt like when she went in to talk about my vision with the teacher, but it was like this is just another example of you trying to get other people to fix me. They ain't gonna fix

me. It's kind of embarrassing because everyone knows this but you. Everyone knows that they're not going to be able to fix me so it's just embarrassing.

Aaron: In other words, it is embarrassing to have your mom go in and keep fighting for a loss cause.

Participant: And that's the thing it's like it makes it sound like I was a horrible person. I thought I was a nice person, I was a good person. I just can't do my schoolwork. It's like someone with one leg and then a person tries to convince them to run a marathon. When are you going to realize that I just can't run this marathon? It's just embarrassing to have you go over to trainer to train him to run this marathon. I still have one leg and I'm not going to be able to do it.

Aaron: Almost like being set up to fail but please don't go out there campaigning for me thinking that this time you're going to secure some research to make a difference because it's not, and then all this has proven to be a failure yet again with yet another lost opportunity.

Participant: Right. The only way this is going to be fixed if I have some internal major epiphany and I stop being lazy. It fundamentally feels like an obese person gets an epiphany that they're going to work out and get thin and they do. That's how it's going to happen.

Aaron: It's almost a wish for the magical whatever it is that I'm not doing right, everyone seems to think that a) I'm not doing right but, b) I can do right. I'm waiting for my train to come in and I get the magic box from the Acme Corporation, the brain helmet and like now I'm rocking.

Participant: Right, exactly. Or something changes internally and my whole perception of life changes, I have a life changing epiphany and everything's sweet. That's what's going to happen. It's not going to be this whole process that happens.

Aaron: It's not going to be solely over time because the process is you're going to affect who you described with your vision therapy and then going back and reassessing

part of your life. You never envisioned that in terms of what's successful. It's like you envisioned this bomb going off.

Participant: If you watch any of the talk shows, it's always like well I made a choice in my life and then everything changed. I'm going to make a choice eventually and somebody's going to change. You can't force that choice and I kept trying and I kept saying this year I'm going to do better at school.

Aaron: You can make all the intentional statements you want and like with the Dr. Phil type, you watch those shows and people come on and at the beginning of the show they're screaming, crying and nothing is right. By the end of the show they go, "Yes Dr. Phil, you're right." Now my whole life is better. It's like they're making these transformations.

Participant: Right and you don't get to see that there's an actually a walk cross that goes into all those transformations. It's really kind of frustrating but you get to the point where it's not frustrating anymore. It's just the fact that why keep fighting because it's just gonna happen sometime or it won't happen at all and I'll just be lazy which is cool too. I'll be lazy and it'll be sweet.

Aaron: So you've been lazy your whole life what's another....

Participant: Eventually you start thinking about "I'm going to draw for a living, it's gonna suck if I'm lazy. What if I get down to it and I am on this dream job drawing, but I'm lazy. I'm lazy, so there's gonna be work. How am I going to do this? I haven't figured this out. How am I going to work at what I enjoy doing and forget about my laziness. It didn't make sense and now it doesn't make sense to think about it but if you enjoy doing it it's not going to be work so you're going to work harder. I think about that now but at the time it was like, I'm lazy and that's a fact. So even what I enjoy doing it's going to be the quality. How do you cheat this laziness gene if medicines don't work and sitters don't work?"

Aaron: We're almost at the end of our interview. My question to you is, is there anything else that you would like to put in or questions you may wish that I would have asked, that I hadn't thought to ask.

Participant: Not really. I usually start talking and it goes places. I don't feel betrayed by society that all these teachers didn't know what was going. But it's like it would be nice if it wasn't the immediate judgment of ADD or the questions weren't asked of me. Like they were seeking answers from me; they were seeking answers from somewhere else or there was some else to turn to for answers. I had no clue, I had no answers. So if there was this other option open it wasn't immediately through ADD it was like well you have a problem that could be ADD or it could be something else.

Aaron: And there's something else I think you mentioned too which was the way you've been exposed to, for example, the idea that there was a vision impairment, it was harder, difficult time-consuming things you even get a grip on because there was no instruction given to you.

Participant: Right.

Aaron: So would you then recommend some kind of introductory process?

Participant: Well more information about it because it was like while I was fixing it, they were telling me what it was. It wasn't as clear to think about for me. Well see while you're doing this what this is doing is it's fixing your eyes because your eyes have such a problem. It would be helpful to go in for the tasks that happen to say we think this is what the problem is. The fact that it was a concrete thing was even more kind of like shady to me because we think this might be a problem. I kind of accepted it first that it's a real problem before I started fixing it that would help.

Aaron: In other words you come to terms with what it is before you begin working to fix it, as opposed to immediately jumping in head-first and trying to do it with good intention and effort, but at the same time you're trying to work out for yourself is this real or not, how is this kind of a thing.

Participant: You're fixing something that you don't think necessarily it's real. So it's like it would be fair to kind of understand that this is the real thing before you start trying to fix it. I was still wrestling with was it real after I fixed it and it seems like it should be established that obviously this is problem but this is what the problem is before you start going and trying to fix it. That would have helped me a lot.

Aaron: In other words, I'm wondering if one can understand something is real before one goes through the experience of having the therapy and seeing the differences over a long period of time or something like that. What can help prepare one for that reality faster, more effectively or even if there are things that can be done just to introduce the fact that this is what we think might be going on. It always felt like it was kind of an isolated thing because we go to this one eye doctor for this therapy, so it was like only one eye doctor.

Aaron: You're a pretty great guy so you must have been like wait a minute.

Participant: Yeah. Is it because no one else believes its true so it was kind of like this almost isolated idea like this is a real isolated incident if it is real. Even though she said she had other patients, other people coming in, it was kind of like there wasn't a public book on it. There wasn't like the odds that the person who was profiting from it was telling us. I didn't say anything that was printed or established other places.

Aaron: Because you couldn't necessarily go find other references to it other than, hey we've got the secret that nobody else has and it costs x-amount per hour.

Participant: I'm not saying the lady I had, Kathy, I really liked her and she was a friend of my mom's friends.

Aaron: Some of it is natural conflicts that have been coming about for you. Alright, I think we've come to the end and if you think of anything else, you're more than welcome to call me or send me an e-mail or something.





## Appendix E

## Additional Chapter II Material

+ The essence of self-concept is that one forms a mental representation of his or her self made up of thoughts, feelings, ideas, and beliefs. These self-representations play a key role in influencing a persons choices, actions and behavior. When they are about the self-concept and self-efficacy of one's self as a learner, the role of representations shed light on the psychological impact and functioning of DVI-LD individuals.

Representations play a vital role in learning and cognition (Markman, 1998). The conceptual representation that a child uses in everyday life may not be scientifically accurate and may contain misconceptions, gaps, quirks, or biases (e.g., Vosniadou & Brewer, 1987). However, good or bad, right or wrong, each child's conceptual representation is a unique, and the effectiveness of his actions and reasoning depends on the representation he creates. (According to Zambo, 2003, p. 1).

Carl Rogers suggested that there can exist significant differences between one's true self, the self that actually exists, and one's ideal self, the self that one thinks one should be but one cannot ever become. The discrepancy between these selves was thought by Rogers to create a fundamental, internal strife (Boeree, 2005).

Rogers' ideas help to understand the notion that a person with LD can be as he is, see him or herself in a different way, and even be perceived by a second party, e.g., adults, teachers, and researchers, in yet another way. The result would then be multiple schisms between one's perception of self (idealized self-concept) and one's actual self. This then describes a process through which the DVI-LD person can come to experience psychological distress resulting from an initially optometric and academic disorder. Further, the idea that there could be multiple schisms suggests that the psychological impact of DVI-LD is complex and multivariate in nature. As such, it makes sense that the psychological aspects are difficult to resolve. These ideas also shed light on the notion that helping an individual with DVI-LD may require seeking understanding of how DVI-LD individuals perceive their disabilities and themselves, and thus influence their own motivation. Without such understanding, it would be difficult to help DVI-LD person alter his or her behaviors, actions, choices, and resulting level of overall academic and professional success (Zambo, 2003).

+ The adult scientific model's conception of students with LD may be more static and specific than that of the students. Specifically, the scientific model may exclude ideas of emotional protection and survival of the self. Put another way, the scientific model may focus more on the academic aspects of having LD and less on the LD student's experience of threat to the self, and needs for emotional safety (Zambo, 2003, pp.1-2).

The sense of empathy for others seems to be a significant psychological factor. Empathy typically improves social success and therefore the development of empathy out of the strain of living with a learning disability can be seen as a real boon. Perhaps as the metaphorical silver-lining of an otherwise dark cloud of academic impairment and resulting low self-concept, self-efficacy, and self-esteem. According to Zambo (2003), Dyslexic students have lowered meta-cognitive ability when compared to non-dyslexic students. This means that they have an impaired ability to reflect on themselves as readers and learners. Yet, the idea of enhanced empathy suggests an increased ability on the part of dyslexic students to reflect on themselves as persons who face adversity and challenge.

+ Additionally, Nowicki's (2003) meta-analysis indicated that social interventions have not been shown to help LD individuals. Further, that the relative lack of success of such interventions "may be reflective of a lack of knowledge about the underlying factors associated with poor social skills" (p.186). Another benefit of the current study is that it may lead to increased understanding about such factors, and therefore contribute to future research on the subject.

+ Significant conclusions can be drawn from Al-Yagon & Mikulincer's 2004 study of attachment factors in LD students. Specifically, that the academic problems of LD do not go away despite: 1) tutoring, 2) punishment, or 3) reward. This makes logical sense since LD arises from neurological and biological problems. No gender differences were found for socioemotional adjustment or academic functioning. Nor did gender moderate the effects of LD on loneliness, sense of coherence, and academic functioning. These findings are significant when considered against Gurian & Stevens' (2004) assertion that "research on gender and

education reveals a disconnect between teaching practice and the needs of male and female brains" (21-26).

+ Students with LD may work harder than their teachers give them credit for (Meltzer, Katzir-Cohen, Miller, & Roditi, 2001), and teachers have been noted to perceive students with LD as less motivated (Grolnick & Ryan, 1990) and less competent (Meltzer, Roditi, Houser, & Perlman, 1998) than typical students" (Martinez & Semrud-Clikeman, 2004, 2nd Paragraph).

+ Motivation:

Engaging in a favorite hobby is an example of intrinsic motivation. The reward is the internal feeling of interest and satisfaction that comes from the activity. When a person is extrinsically motivated, he or she engages in the task to acquire some outside reward or avoid external punishment. The classic example of this is earning high grades in school because you are given money for each high grade, or to avoid being criticized or punished by a teacher or parent (Deci & Ryan, 2000).

Extrinsic motivation varies depending on the amount of autonomy inherent in a given task. An extrinsic reward that comes from an activity that the individual gets to choose

will be less problematic than if the same reward came from an activity that was forced on the individual.

For example, a student who does his homework only because he fears parental sanctions for not doing it is extrinsically motivated because he is doing the work in order to attain the separable outcome of avoiding sanctions. Similarly, a student who does the work because she personally believes it is valuable for her chosen career is also extrinsically motivated because she too is doing it for its instrumental value rather than because she finds it interesting. Both examples involve instrumentalities, yet the latter case entails personal endorsement and a feeling of choice, whereas the former involves mere compliance with an external control. Both represent intentional behavior, but the two types of extrinsic motivation vary in their relative autonomy (Deci & Ryan, 2000, p.60).

Another concept introduced by Deci & Ryan (2000), is that there appears to be a pattern to how the two types of motivation function over the course of schooling.

Although intrinsic motivation is clearly an important type of motivation, most of the activities people do are not, strictly speaking, intrinsically motivated. This is especially the case after early childhood, as the freedom to be intrinsically motivated becomes increasingly curtailed by social demands and roles that require individuals to assume responsibility for non-intrinsically interesting tasks. In schools, for example, it appears that intrinsic motivation becomes weaker with each advancing grade (p.60).

The difference between intrinsic and extrinsic motivation is significant. There exists more than 30 years of research that shows that the quality of experience and performance differ when one is behaving for intrinsic

versus extrinsic reasons (Deci & Ryan, 2000, p.55). Deci & Ryan (2000) observed that intrinsic motivation results in high-quality learning and creativity in matters of learning and, therefore, "it is especially important to detail the factors and forces that engender versus undermine it" (p. 55).

### *Cognitive Evaluation Theory*

Cognitive Evaluation Theory (CET) is the fourth theory that describes motivation.

Cognitive Evaluation Theory (CET) was presented by Deci and Ryan (1985) to specify the factors in social contexts that produce variability in intrinsic motivation. CET, which is considered a sub-theory of self-determination theory, argues that interpersonal events and structures (e.g., rewards, communications, feedback) that conduce toward feelings of competence during action can enhance intrinsic motivation for that action because they allow satisfaction of the basic psychological need for competence. Accordingly, for example, optimal challenges, effectance promoting feedback, and freedom from demeaning evaluations are all predicted to facilitate intrinsic motivation.

CET further specifies that feelings of competence will not enhance intrinsic motivation unless they are accompanied by a sense of autonomy or, in attributional terms, by an internal perceived locus of causality (IPLOC; deCharms, 1968). Thus, people must not only experience perceived competence (or self-efficacy), they must also experience their behavior to be self-determined if intrinsic motivation is to be maintained or enhanced. Stated differently, for a high level of intrinsic motivation people must experience satisfaction of the needs both for competence and autonomy (Deci & Ryan, 1992, p.58).

As was described in the self-concept and self-esteem areas of this review, finding a non-academic task that one can succeed at can protect LD students self-concept and self-esteem. If one focuses on an area of personal interest that one can be successful in, e.g., building model airplanes, CET suggests that person will experience intrinsic satisfaction and motivation. "According to Deci and Ryan (1992), increased conceptual learning, creativity, flexibility, positive emotional health, and higher self-esteem have all been associated with intrinsically motivated activity" (Rilett, 1997, p.4).

+ Skinner and Belmont (1993) developed a model that proposed that students would reach their highest potential of engagement when the students' basic psychological needs to be competent, autonomous, and involved with people were met (Rilett, 1997, p.16). The model sited three key variables that could be optimized by teachers: Providing structure, e.g., clear expectations; autonomy support, e.g., choice of which learning activities would be engaged in; and optimal involvement with students, e.g., the teacher takes time to have enjoyable and appropriate affectionate interactions with students, or dedicating



resources to students. Rilett (1997) pointed out that the opposite of having such structure, autonomy support, and involvement would be, respectively, chaos, coercion and rejection, or neglect.

According to the Theory of Active Vision proposed by Findlay and Gilchrist (Cole, 2004), the eyes of a DVI individual may not be able to stay trained on the source of stimuli and information, thus the person is literally fighting with his or her eyes to stay targeted on that which is to be attended to. Attention span is in this way a mechanically induced by the motion of the eyes and the processing of vision. This contrasts with the commonly held assumption that paying attention to things is a personal preference or choice. In education, this has relevance because teachers may tend to interpret paying attention to personal choice, and the lack of same as a deliberate intention to be lazy or avoid responsibility.

+ DVI-LD student metaphor:

Mine workers have been known to bring small birds with them into the deep underground. The logic behind this was that the bird would sing and chirp when all was well. However, when poisonous mine gasses built up to toxic

levels, the birds would stop singing. Usually this was due to the birds small size which led to them dying of poisoning or asphyxiation before the miners. There may be a parallel between the birds and LD students: In an learning environment or student-teacher interaction that becomes toxic, the LD student may simply succumb to the stresses that face all students. LD students simply succumb to them faster because they have a more intense toxic experience. Given the importance of this influential relationship, it is logical to explore some of the specific interactions LD students and their teachers have regarding motivation, or the lack thereof.

+ In the same way, these visual system skills are needed for many sports from archery to volleyball. Impairment in sports performance may be deeply discouraging to an individual. It could lead to a lack of self-efficacy and confidence. Young boys are known to socialize through rough play such as that found in sporting competition. A male with DVI may have great difficulty shooting a ball through a hoop, catching a pass or even striking an incoming ball. The result could be a loss of social standing and self-confidence. This may in turn form an interruption in the

normal development of social skills. Later in life, organized sports are regarded as a good way to keep children out of negative activities such as running with gangs or using drugs. It would therefore be logical to conclude that becoming alienated from sports and positive peers who play them somehow sets the DVI individual up for delinquent behavior.

#### + Identifying DVI:

When DVI is identified, it can be treated with Vision Therapy. Cohen (1988) says that Vision Therapy is also called vision training, orthoptics, eye training and eye exercises. It is also sometimes referred to as Behavioral Vision Care (BVC).

Although DVI significantly affects an individual, a question still remains as to how big of a problem DVI is in our society. Exactly how many people does DVI affect in the United States?

#### + *Theories of Motivation*

According to Rilett (1997), There are three main theories of how motivation works in young children: 1) Bandura's self-efficacy theory, which refers to students'

beliefs and perceptions about their capability to apply skills and knowledge to academic tasks; 2) attribution theory, which is concerned with how a student attributes causes of success and failure in a given situation; and 3) self-regulated learning theory, which hypothesizes that a student will be more likely to experience to be motivated to learn when he or she depends on his or herself while applying planning and integrated cognitive skills toward academic tasks (p.2). A fourth conceptualization, Cognitive Evaluation Theory (CET) (Deci & Ryan, 2000), appears to incorporate the fundamental ideas of the first three (Rilett, 1997).

+ *Gifted but Learning Disabled*

Having LD is not limited to those of low intelligence or creative capability. LD is also not a synonym for being of low intelligence or limited creative capability. In other words, LD can exist in anyone, including those individuals frequently referred to as gifted. Gifted-LD exists as a subcategory of LD. Gifted individuals may be described as intelligent, innovative, creative, self-motivated, self-directed, and self-actualizing learners. Gifted students are also referred to as academically

talented. Gifted individuals tend to have significantly above average I.Q. scores and devote large amounts of energy and time to exploring and mastering material and skills they find personally satisfying and intrinsically motivating. Research indicates that these students encounter negative experiences during primary and secondary schooling due to their dual exceptionality as both gifted and learning disabled (Reis & Colbert, 2004).

The scope of the problem is illuminated by Davis & Rimm (2003) who cited estimates that 120,000 to 180,000 gifted students have learning disabilities and currently attend American schools (Paragraph 6 in the full text). It has been observed that resilience, a key factor in accomplishment and life satisfaction of LD individuals (see Resilience section, Chapter II), is enhanced by having a higher I.Q.. However, there is a danger in having high I.Q. and LD as well:

Intellectually gifted individuals with specific learning disabilities are the most misjudged, misunderstood, and neglected segment of the student population and the community. Teachers, school counselors, and others often overlook signs of intellectual giftedness and focus attention on such deficits as poor spelling, reading, and writing. (Whitmore and Maker, 1985, p.204).

Specifically, gifted-LD students frequently exhibit feelings of inferiority, inability to persevere to

accomplish goals, and show a lack of self-confidence (Reis & Colbert, 2004).

Current research indicates that it is the interaction of high ability and learning disabilities that may cause confusion and create social and emotional difficulties for students as they struggle to understand why they can know an answer but not be able to say it or write it correctly (Olenchak; Reis et al., 1995). (Reis & Colbert, 2005, Paragraph 12 of full text).

The research on gifted-LD reveals psychological implications of having LD. Those who have LD exist along a range or continuum that could be described as mild impairment at one end, and severe impairment at the other. An individual person's location in that continuum must be evaluated on the state of numerous factors, e.g., Academic talent and high I.Q..

+ Two significant areas of psychology research literature have been described in this section: 1)The self and its three components, and 2)resilience.

self x 3 looked at the impact of LD and by extrapolation DVI on the self and its functioning. Self x 3 looks at the differences between LD and non LD students. Resilience looked at contextual factors for why some people with LD succeed where others do not.

Self x 3 research proceeded from the general theory that LD leads to suffering, and that those with LD need special help that those without LD don't need. The research produced unreliable results: Sometimes LD kids were found to have lower self x 3 than non-LD. Other times these differences were found to be the result of poor research execution or faulty methodological design. There was a confusion in the research community about if there were any real differences and how significant they were relative to the population. In a way, these studies looked at the individual and his or her LD out of context. It was searching for universal truism, as in "If you have LD then you are going to have lots of problems that you won't otherwise have."

The resilience research looked at the context of the LD person in his or her environment. And identified an important variable: Not all LD is created equal. That is, LD is in fact a broad term that describes not one or several concrete learning disabilities, but a multiple of variables that operate on individual continuums. E.g., Age of onset, severity of symptoms and impairment, co-morbid factors, etc. These factors not only influence what the LD

is but how it express itself. The factors also influence each other, presumably.

So, self x 3 looked at the individual out of context for universal truth, the resilience research looked at the context specific factors of LD. Also, what changes can happen that influence a person's overall success in spite of LD. Together, they overlap at a common point: LD expresses itself uniquely dependent upon the types of LD present, and the situation in which they express themselves, in combination with the in-person factors of each individual. Together, they forge an experience that the person has, as in living each day faced with learning related challenges, and shape the person's experience of who he or she is. This then can function as a self-fulfilling belief system. My learning disabilities cause me to do poorly, but then I see myself as as damaged and expect to fail, and therefore I do poorly.

The implication of these findings is the research supported perspective that LD is a significant problem that must be individually approached, assessed and comprehended.

Also, the self x 3 research started to look at context. The research looked eventually outside of the deficit approach and examined the context in which LD people were



being studied. The result was that external factors such as the teacher's outlook on LD (did the teacher believe the LD person was helpable and therefore cultivate supportive, interactive relationships with LD students? Or did the teacher believe the LD person to be permanently and neurologically damaged and as a result avoided interaction with and support of LD students?)

+ DVI lies at the nexus of optometry, education, and psychology. It is an identifiable and to some extent treatable problem especially if detected and treated early in life. DVI tends to function as a learning disability in educational and academic contexts, and can produce chronic frustration and other forms of emotional distress that lead to lowered self-concept, self-esteem, and self-efficacy. These negative conceptions of self, and the vicious cycle of lowered expectation, perceived failure of the self, and other negative life impacts they give rise to, brings DVI firmly into the realm of psychology. However, even though much is known about the psychological impact of learning disabilities in general, little is known about the psychological impact of DVI in particular.

+ According to Biaggio and Bittner (1990), "a number of vision conditions have psychological components and some psychological conditions may be complicated by vision difficulties: Thus, there are a number of ways in which psychologists and optometrists could inform each others' practices" (p.1313).

+ Overall, the field of learning disability research has moved from a deficit model that explores the limitations and impairments of having a learning disability, to a resilience model that explores the interaction between internal and external factors. This shift seems to be the consensus direction that the field of LD research is moving; suggesting an overall agreement among researchers as to the validity and efficacy of the resilience model and its philosophical orientation (Margalit, 2004; Margalit, 2003; Cosden, 2003; Meltzer, 2004; Olufs, 1996). Bryan (2003) summed up the benefits of the risk and resilience framework:

Two factors render this framework particularly inviting...First, it is inherently optimistic because it assumes that once we identify factors that contribute to resilience, we can train less-resistant individuals to be more resilient. As such, it moves us away from the deficit models to empowering models. Second, the model forces us to look beyond the characteristics of the individual to consider external factors that have a

significant influence on development and behavior. (p. 94).

Bryan also cautioned that it would be premature to give up current treatment models before fully exploring and developing the risk and resilience model. Donahue and Pearl (2003) agree that, despite its promise, careful consideration must be taken before the lens of risk and resilience is adopted as the primary mode of approach to LD. Specifically, these two researchers call for four particular questions to be asked: "What do we mean by risk and resilience factors? How do we characterize learning disabilities as risk factors? 'At risk' for what? How should this framework guide intervention efforts? (pp. 90-93)" While these questions represent a note of cautious, methodical consideration and implementation of resilience, they do not on their own contradict the implied value of resilience as a model for comprehending the outcome of having LD. To wit:

Experts in the field of learning disabilities have long recognized the importance of affective characteristics such as motivation, self-concept, and locus of control on the ability of students with learning disabilities to succeed academically. Substantial amounts of research have indicated that the prolonged failure experience of individuals with learning disabilities profoundly impact affective development. A weakened academic self-efficacy may evolve which undermines motivation to use coping strategies to enhance success. A difference in resilience appears to be a major factor behind the success of some

of the individuals. These differences are predicated on disparities between the manner in which individuals with learning disabilities view themselves and the educational process, as well as the educational and familial support available (Olufs, 1996, p.x).

+ Imagine a student who has the following experience each day: he or she will go to a place where fatigue, discomfort and cognitive sluggishness are chronic experiences. He or she will be put to virtually undoable tasks throughout the day. Poor grades and disapproval from teachers will be a constant feedback. No matter how frustrated the student is, no quarter or understanding will be given. It will be suggested to him or her that the main problem is a lack of personal desire to succeed, to work hard and give effort. Yet, no matter how hard the student tries, the work will remain overly difficult. As the student reaches the point of fatigue where no more visual work can be achieved, chronic boredom will set in. Without the ability to continue on with school work, the classroom becomes a prison. Any behavior that the student engages in to distract him or herself from this experience, such as seeking to elevate mood through joking with peers and cohorts, will result in punishment. Now, imagine if this experience awaited this person for 7-8 hours per day, 5

days a week, for more than 38 weeks per year, and for a minimum of 10 years.

+ Even though academic problems may remain chronic, contextual protective and risk factors, e.g., resilience and vulnerability, are important determinants of adjustment and success for those with learning disabilities (Sorensen et al, 2003).

+ It may be valuable to consider that there are positive benefits and outcomes associated with DVI and its phenomenon. For example, an individual with DVI may develop strong listening skills and a florid imagination as compensations for visual difficulties, poor attention span, and boredom. While the primary researcher certainly holds a space for these kinds of strengths, he simultaneously acknowledges the fact that the available literature on the subject seems exclusively focused on the limitations, disadvantages and struggles of those with DVI. However, it can be instructive to consider that the words used in the literature search itself, such as "impairment, disability, and loss", may tend to yield material addressing problems rather than benefits. Similarly, the literature search

focused on areas of study such as psychology and optometry, which are themselves sufficiently concerned with deficits, problems and troubles as to yield negatively oriented perspectives and information. The next section focuses on the position of the proposed study in the greater context of psychology.

+ A comparison of the DVI results with the ideas in the literature review can produce more insight into the experience of DVI and stronger connection with the greater body of literature on LD. This could lead to the accomplishment of the mission of this study, which is to Further, the results of this study could yield data about DVI that enhances, informs, or further explicates information on LD. Specifically, as it was mentioned above, there can be a significant difference between an LD person's conceptual understanding of a phenomenon and that of researchers and experts. Since a person's conception of a problem or circumstance heavily determines his responses and actions toward it, it seems vital to create valid alignment between the concept of those who have DVI and those who study and treat it. This study may help to align

those concepts through a qualitative exploration of the experience of having DVI

+ *Self-Efficacy, Self-Concept, & Self-Esteem*

Having DVI-LD affects the psychological self of an individual. In the literature, the self is frequently defined, discussed, and explored visa-vis three related constructs that together compose the self: Self-efficacy, self-concept, & self-esteem. A discussion of these three concepts, their definitions and their interrelationships follows. Understanding the concept of the self and its three components is essential to comprehending the psychological impact of DVI-LD.

Self-Efficacy:

An individual's estimate of his ability to cope with a situation, and outcome expectancy; an individual's estimate of the likelihood of certain consequences occurring. This combination of assessments of potential threat and coping resources determines how anxious an individual may become in a given situation. (Rubin, 2004, General Information section).

Academic Self-Efficacy is a related concept that refers to a person's beliefs about his or her ability to succeed or fail to achieve desired academic outcomes. This type of Self-Efficacy has particular bearing on the discussion of DVI-LD. Self-efficacy appraisals were found to become more

frequent and significant when the person is presented with novel tasks or when standards for success are ambiguous (Bong & Richard, 1999). Such circumstances occur frequently in the scholastic life of an LD student. However, "in most instances of efficacy appraisal, one's past mastery experience wields stronger influence than do other sources of efficacy information, such as vicarious experience, verbal persuasion, and physiological reactions (Bandura, 1977)" (Bong & Richards, 1999, Nature of Comparison Frames section).

Self-Concept or Self-Image: "The composite of beliefs and feelings that is held about oneself at a given time, formed from the internal perception and perceptions of others' reactions" (Boston College, 2005, Key Concepts page). In addition,

many of the successes and failures that people experience in many areas of life are closely related to the ways that they have learned to view themselves and their relationships with others. It is also becoming clear that self-concept has at least three major qualities of interest to counselors: (1) it is learned, (2) it is organized, and (3) it is dynamic. (Wikipedia, 2006).

Harter (1999) explained that feelings of low global self-worth, a component of Self-Concept that touches on overall feelings of happiness, satisfaction, and feelings about oneself, is associated with motivation problems and



depression. Self-concept is a complex construct that incorporates both cognitive and affective responses toward the self and is influenced heavily by social comparison (Bong & Clark, 1999). In one study, Renick and Hatter (1989) found that 84% of LD children compared themselves with their normally achieving peers.

Self-esteem: "Feelings of self-worth stemming from the individual's positive or negative beliefs about being valuable and capable" (Philpot, 2002). In psychology, self-esteem or self-worth includes a person's subjective appraisal of himself or herself as intrinsically positive or negative to some degree (Sedikides & Gregg, 2003).

Self-esteem involves both self-relevant beliefs (e.g., "I am competent/incompetent", "I am liked/disliked") and associated self-relevant emotions (e.g., triumph/despair, pride/shame). It also finds expression in behavior (e.g., assertiveness/

timorousness, confidence/caution). In addition, self-esteem can be construed as an enduring personality characteristic (trait self-esteem) or as a temporary psychological condition (state self-esteem). Finally, self-esteem can be specific to a particular dimension (e.g., "I believe I am a good writer, and feel proud of that in particular") or global in extent (e.g., "I believe I am a good person, and feel proud of myself in general"). (Wikipedia, 2006, Self-esteem).

The phrases "sense of self" and "the self" are used in this study to infer the total construct called "self" that is composed of self-efficacy, self-concept, and self-esteem. (See Appendix E for more information). The three

concepts of self are related but not synonymous. Self-efficacy, which can be predicted to be quite low in the case of DVI, quickly intrudes upon self-concept. It inclines the individual with DVI to have a self-concept contaminated with a sense that he or she cannot achieve goals, or succeed in academic situations. Thus, self-worth suffers as one comes to affective judgments and conclusions of what it means to lack efficacy (Bong & Richard, 1999).

Another dimension of self-efficacy and self-concept is that during the younger years, a child's self-concept is heavily influenced by outcomes. In later years and especially into adulthood, self-concept becomes a more causal force (Bong & Richards, 1999).

+ Deficit Framework Quote:

The deficit framework has systematically ignored critical contextual factors that interact with child variables (e.g., self-efficacy, attitudes toward school, internalizing symptomatology, personality) to facilitate (or impede) healthy psychosocial adjustment. (Martinez & Semrud-Clikeman, 2004, p.7).

+ The current research study is designed to gain information that will help professionals better understand and therefore better treat DVI individuals. The value of this study is founded on the certainty that DVI, once discovered, can be corrected and improved. It is important to study DVI because "traditionally, epidemiological

studies of vision loss in populations have focused almost exclusively on recognition acuity measured at a distance. Almost no population data exist that describe the prevalence of near-vision loss based on standardized examination techniques. (Tielsch, 2000, p.7)"

#### + Motivation

The news on those LD students who do attend college is not entirely negative. An unexpected benefit of having LD is that those who make it to college demonstrate more resiliency and achievement motivation than non-LD students (Hall, Spruill, & Webster, 2002). While Borokowski et al., (1990) found that LD individuals are more likely than non-LD individuals to have external rather than internal locus of control, Hall, Spruill, & Webster (2002) reported that college students with LD show significantly higher scores on the Need for Achievement Scale than their non-LD counterparts. The "need for achievement is the motivation to strive for success, to master difficult challenges, and to meet high personally generated standards of excellence (McClelland, 1985)" (Hall, Spruill, & Webster, 2002, Introduction).

Hall, Spruill, & Webster (2002) found that college students with LD were also reported to show more resiliency

and initiative than their non-LD counterparts, while reporting experiencing less stress. The explanations put forth for these findings are that LD college students have faced more challenges earlier in their lives and developed more effective ability to handle stress. Another possibility is that LD students who have made it to college did so by seeking to achieve at a high level regardless of the challenges they experienced. A final possibility is that LD individuals misperceive their stress level and are simply unaware of the difficulty that they experience. These findings point to the idea that the challenge of LD can motivate an LD individual to achieve above and beyond his or her non-LD peers. There are other factors which influence LD students motivation, chief among those are the influence of parents and teachers.

Secondarily, teachers in the Al-Yagon & Mikulincer study showed "lower levels of emotional closeness to children with learning disorders than to the typically developing students in their classrooms" (Al-Yagon & Mikulincer, 2004, 19th paragraph in full text). One encouraging finding is that as much as general attachment style can influence an LD person's beliefs about security and, thus, attachment

related behavior, positive experiences can impact a person as well. Specifically, individual positive experience with a supportive, attachment-enhancing teacher can help an LD person form effective beliefs and behaviors that enhance positive attachment. What this means is that a single teacher can positively affect even a low-secure attachment style LD student. Thus, there is a functional model for improving attachment, relationships, and overall social ability for LD students.

Clark (1997) reported several conclusions about teachers views and beliefs relative to LD students. First of all, teachers see low effort as the primary reason for academic difficulty. When it comes to students giving low effort, teachers tend to view the child as responsible for his or her outcomes. Teachers reported becoming angry when a child who gives low effort failed on a test. As a consequence, teachers will punish a low effort child more and reward him or her less than a regular effort peer. Teachers react by giving feedback cues to LD students that they are learners who cannot be successful. LD children then tend to adopt these views as valid judgments by a significant authority figure of their capabilities (self-efficacy) and self-worth (self-esteem).

## Psychology

Children with learning problems can suffer from anxiety (Margalit & Zak, 1984), depression and suicide risk (Huntington & Bender, 1993), reduced social competence (Merrell, 1991; Tsatsanis, Fuerst, & Rourke, 1997), and behavior problems (Merrell, 1991). In addition, children with learning problems are described as having lower self-concept, particularly in the cognitive and academic arenas (Kistner & Osborne, 1987; Grolnick & Ryan, 1990; Harter, Whitesell, & Junkin, 1998). (Sorensen et al., 2003, p.10).

Nowicki (2003) cites findings that demonstrate learning disabilities "can increase a student's likelihood of victimization by schoolyard bullies" (p 172). The danger of such bullying is the threat to the child's development of social skills, self-concept, and self-esteem.

Victimization can result in a sequence of events, beginning with increased social anxiety that may eventually lead to less frequent social contact. Having fewer friends, in turn, can make a child a better target for bullies. Consequently, the sequence is linked into a cycle of poor social success and loss of self-esteem. (Nowicki, 2003, p. 172).

Nowicki (2003) found that LD children preferred classmates without LD. Reasons for this vary from a preference for more socially skilled peers to the increased status afforded to those peers and to their friends (p. 185). This is a complicating factor because it suggests that LD students, who are more vulnerable to bullying, are actually drawn away from LD peers who might, as friends,

insulate them from availability and the impact of being bullied. In addition, LD individuals are more likely to be drawn toward those who are more likely to bully them, i.e., non-disabled peers. In other words, LD children appear drawn into their vulnerable social state by their preference for the company of those who are unlike them.

Although we all expect to experience failure at some points in our lives, individuals with learning disabilities typically experience recurrent failure early in their academic careers, running head-on into academic challenges and experiencing the resultant frustration. When this inadequacy occurs early in the elementary career, many students are unprepared for the failure experiences and have few coping skills...students with learning disabilities typically experience peer rejection and low self-esteem and self-efficacy along with the academic challenges. (Olufs, 1996, p.43).

As early as kindergarten, LD students already demonstrate deficits in cognitive social functioning and social skills relative to non-LD peers (Margalit, 2004). Social skills consist of the ability to exhibit appropriate behaviors in specific social circumstances and situations, including self-control, cooperation, sharing, comprehending the needs of others, and the ability to initiate and maintain social interactions (Nowicki, 2003).

Nowicki (2003) reported that LD children and their low-achieving classmates tend to have inaccurate self-

perceptions of social acceptance. Somehow, LD students tend to perceive themselves as socially on par with their peers. At the same time, the peers of LD students tend to rate them as having lower social standing and status (Gans, Kenny, & Ghany, 1997). There seems to be a psychological mechanism that allows the LD individual to view him or herself as both impaired (having a hard time with school work) and typical or normal. This is reflected in other research that found LD individuals often maintain a positive sense of global worth (i.e., they feel valuable as human beings) at the same time that they harbor a low academic sense of self (e.g. felt worse about their general intellectual ability than their normal peers did).

Dyslexia, another apparently neurologically based problem that like DVI leads to significant reading problems (Zambo, 2003, pp.103-106).

The Zambo (2003) research also indicates that there a difference between an LD student's perception of his disability and that of teachers, tutors, and researchers in the field.

I know that students with dyslexia construct a conceptual representation of reading that is very much like those of researchers but with some profound and obvious differences. The students' models contain ideas about themselves and reading nested in an emotionally intense and imaginatively rich way. They understand the



status and power that reading brings and are sensitive to the judgments and labels that they receive. These eleven students recognize that reading is important and can be a positive force in their lives but that it is a painful and destructive one as well. Because of this hurt in their representations children with dyslexia become emotionally exhausted and empathic toward each other. (Zambo, 2003, p.118)

These studies reveal a potentially significant psychological aspect of LD: Splitting of the sense of self between global and task specific (academic self-concept) self-efficacy, self-concept, and self-esteem. It seems logical that global sense of self is protected by creating perceptual barriers between it and task specific realms of self-efficacy, self-concept, and self-esteem.

Students beliefs about the three parts of self are often obtained through questionnaires and other self-reporting tools. The question is, do these tools provide clear, universal definitions or ones that are subjective and open to interpretation? Other problems have been reported including comparing the results of experimental groups to population norms rather than to control groups; heavier reliance on correlational rather than experimental designs; and the use of unspecific contexts; undifferentiated age groups; presumptions on the part of researchers and devices (i.e., questionnaires and other tools) that self-concept is

uni-variable or uni-dimensional construct (e.g., it is either high or low) rather than a multivariate construct; and the use of undifferentiated populations, e.g., mixed groups participants who have physical as well as academic disabilities (Gadeyne, Ghesquiere, & Onghena, 2004; Bong & Richards, 1999). Conflicting conclusions about the cause, correlation, and effect are found in the research.

Learning disabilities and juvenile delinquency have been linked by the National Institute for Juvenile Justice and Delinquency Prevention (NIJJDP) through a study by the Association for Children with Learning Disabilities (ACLD) and the National Center for State Courts (NIJJDP, 1976). Since DVI acts as a learning disability, and learning disabilities are linked to delinquency, there exists a direct connection between DVI and delinquency.

+ There are not only variations in types of LD, but in age of onset, impact of gender, severity of disability symptoms, presence of high or low native intellect, and more (Gadeyne, Ghesquiere, & Onghena, 2004). While a logical extrapolation can be made from the psychology of LD to the psychology of DVI, the former does not completely

describe the latter. Individuals with DVI may have different challenges and benefits and therefor different experiences, from individuals with other specific types of LD. In order to know the impact of having DVI, it must be studied specifically, using DVI rather than generally LD populations.

The scope of this study is the subjective experience of individuals who have DVI. The phrase "subjective experience" refers to a person's unique perceptions of the impact, meaning and effect of DVI on his or her life.

## Appendix F: A Metaphor of Life With DVI

As I consider the experience of having DVI, I am aware of an undercurrent of feeling. Deep down beneath the surface a swift and powerful river of pent up emotion, frustration, need, desire and defiance course. And yet, they feed into a great ocean of glory, as of when a person surmounts the difficulty of climbing a great peak. At the summit, the journey upward means less than the view at the top.

You look around and see the terrain of your life. You can see the marshes of your youth, the bogs of difficulty that you traversed. Yet, you knew no other way. It was the way it was. And you marched forward, ever seeking the sunlight. Once in a while you felt the warm sunshine rays of freedom, peer acceptance and other joys. These were your boon, they fed you in times of hunger and they comforted you in times of suffering. And there, at swamp's edge, as you got older, you found a more solid purchase. The earth became firm beneath your feet, your strength grew, and your determination not to give in to the bog was forged. No one on Earth could make you stay there, and you moved forward. As you gained the freedom and power to make determinations for yourself, you found that the swamp behind mattered

less. And you marched up the long, slow, steady incline toward the root of the mountain.

You looked back and finally had perspective and could see the mire for what it was, an ill place in the world rather than the whole world itself. Yet, your troubles, your limitations, your DVI, it was as nothing. It didn't stop you. And to lament it would only be to give your suffering more power over you. Only to load yourself with more baggage to slow and impede your journey away from it. You make a decision, or perhaps reaffirm a decision you made long ago, you will not carry that weight upon. Others, your taskmasters, will have to make you carry it if you are to carry it. You feel great strength and are keenly aware of your desire to be free. Your journey makes you go alone, no one else seems to understand, relate to or care much about the process of your struggle. They simply urge you up toward success. You do not care much for their desires. You have your own. You want company, camaraderie and acceptance. You look for any and all who would let you prove yourself. You wish to see yourself as an equal in your mighty company. Yet, there are costs to this. You may find your way toward treacherous precipices where you use

your daring do to prove your worth. You take risks, you secretly yearn for any chance to prove your worth.

You experience a disconnect between your believe that you face no significant problem and your understanding, perhaps only at an implicit level, that something has stood in your way for your entire life.

An unseen weight hangs about your soul. It fatigues you, stresses you and over stimulates you. Everything is harder, yet you march on. You look up one day and find, to your surprise, that you have been climbing the mountain for a long time. The mountain is symbol of success and achievement, of self-respect and high status, of worth and desire. When you were in the bog, the teachers and parents seemed exasperated with you. Their criticism seemed a prophecy, that if you did not correct yourself back then, then you would never be able to climb the mountain. You realize here and now that they were wrong. Or at least, that prediction and action are not the same thing. You are confronted with contradictory feelings and evidence: You are strong as evidenced by your climb upon the mountain, yet you are afraid because some part of you feels weak. They were right about your performance but they were wrong in their understanding of why you arrived at your outcomes.

You are sure of where you have come from, but cannot imagine where you are going to, in terms of success.

And now you stand upon the mountain's roof. You look out and see, as an adult, the peculiar but amazing path you took to get here. You feel a deep joy and yet a powerful sorrow. Did your climb need to be this arduous? Did you have to suffer as much as you did. And you wonder about how you might have gotten here otherwise? It is not as simple as to say "I love my limitations because without them I would not be here, nor be who I am." This feels like a rationalization. Like a copout. Like a way of accepting that which, at some level, you fought against your entire life. There is in that moment a fear of betrayal.

And you feel something else, as you smell the sweet, cool winds: A deep desire to help others up their mountain. Because regardless of what you accept about yourself, your journey and your experience, you intuitively know that people who face what you did need help. The more help the better, yet the help must be the right kind. Had you been told you were broken and needed help, then you would have fought it with all your might. To accept help as a broken person is to admit to being weak, powerless, and a diminished person. You know now, standing on the roof of

the world, that a person like you would need to be handled differently. Challenged to succeed, offered help that he or she could take or leave.

You know that whatever is done to offer help to the DVI individual, it is vital to recognize the dignity of the DVI individual. The person has strength, ability and courage. Nurture these qualities if you want to nurture the DVI individual. Get him or her the proper diagnosis and the right vision therapy. Help his or her school personnel understand the nature of the visual and perceptual challenges that are faced.. It is better to encourage and inspire the person than to approach him or her as a defective, impaired, low status individual.