

TRUDY'S TRIUMPH: A NARRATIVE LIFE HISTORY OF  
AN ADOLESCENT SURVIVOR OF ABUSIVE HEAD TRAUMA

by

Crystal G. Ledford

Liberty University

A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

Doctor of Education

Liberty University

2017

TRUDY'S TRIUMPH: A NARRATIVE LIFE HISTORY OF  
AN ADOLESCENT SURVIVOR OF ABUSIVE HEAD TRAUMA

by Crystal G. Ledford

A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

Doctor of Education

Liberty University, Lynchburg, VA

2017

APPROVED BY:

Gail Collins, Ed.D., Committee Chair

Lucinda Spaulding, Ph.D., Committee Member

Nanci Howard, Ed.D., Committee Member

## ABSTRACT

The purpose of this narrative study was to describe the life history of an adolescent survivor of an abusive head trauma in the Southeastern United States. Abusive head trauma is a form of inflicted brain injury, often occurring because of violence in the form of shaking or impact to the head of an infant under the age of two years old (Chevignard & Lind, 2014). Life history is defined as a first-hand account to convey understanding of a life. The primary participant was a 19-year-old, Caucasian female survivor of an abusive head trauma that occurred when she was five months old. Secondary participants include the survivor's family members, a family friend, a special education teacher and a church youth leader. The theoretical framework of this study was based on Bronfenbrenner's (1979) ecology of human development, Ungar's (2012) theory of social-ecological resilience, and Bandura's (1986) social cognitive theory. The central research question was: What are the lived experiences of an adolescent survivor of an abusive head trauma in the Southeastern United States? Data was collected through interviews, observations, documents, artifacts, video journal, and prolonged engagement with the survivor and her family. Data was analyzed to describe the story and place it in a chronology to present narration focusing on processes, theories, and unique general features of the primary participant's life. Findings indicated that the primary participant faced neurological, cognitive, behavioral, academic and social challenges, while her resilience mechanisms included a large support network, adaptive behaviors, faith and perseverance. This study makes an original, empirical contribution as the sole account of the life history of an adolescent survivor of an abusive head trauma.

*Keywords:* life history, traumatic brain injury, abusive head trauma, resilience, adolescent

**Copyright Page**

© 2017 Crystal G. Ledford

### **Dedication**

To Trudy, a beautiful child of God, and all children who have suffered abuse at the hands of those who are supposed to love and care for you the most, I dedicate this work. I pray that justice will prevail and that you and others will find hope and purpose in your life story.

## Acknowledgments

*“For I know the plans that I have for you, says the Lord, plans to prosper you and not to harm you, plans to give you hope and a future”* Jeremiah 29:11

First, and foremost, I want to thank my Lord and Savior, Jesus Christ for allowing me the opportunity to accomplish a goal that I once never thought was possible and for equipping me with the courage and abilities to see this journey to its end. I am completely humbled and unworthy of His grace and mercy, but forever grateful for His love for me.

Second, I want to thank my amazing committee. A special debt of gratitude is owed to my chair, Dr. Gail Collins for her unwavering dedication, guidance and prayers throughout this process. I thank Dr. Lucinda Spaulding for encouraging me to find a topic that I could be passionate about and for her prayers and insightful advice throughout this process. I would also like to extend thanks to Dr. Nanci Howard for providing thorough feedback so that I could honor Trudy’s story.

Third, I want to thank all of the precious students who have passed through my classes as a high school teacher and who have held me accountable for seeing this work through to completion along the way. You will always be in my heart.

Finally, I owe the deepest debt of gratitude to my wonderful soulmate and love of my life, my husband, Barry, whose tireless support and endless encouragement has allowed me to persevere and to finish this journey. I thank my two beautiful children, Reese and Cooper for the sacrifices that they have made to allow me to be able to achieve this accomplishment. I thank my parents for teaching me to persist through difficult times and my brother, sister-in-law and two beautiful nieces for their unwavering encouragement. This is for you.

## Table of Contents

ABSTRACT.....	3
Copyright Page.....	4
Dedication.....	5
Acknowledgments.....	6
List of Tables .....	11
List of Abbreviations .....	12
CHAPTER ONE: INTRODUCTION.....	13
Overview.....	13
Background.....	13
Situation to Self.....	17
Problem Statement.....	19
Purpose Statement.....	20
Significance of the Study.....	21
Research Questions.....	22
Definitions.....	24
Summary.....	26
CHAPTER TWO: LITERATURE REVIEW.....	28
Overview.....	28
Theoretical Framework.....	29
Bronfenbrenner’s (1979) Ecology of Human Development.....	30
Ungar’s (2012) Theory of Social-Ecological Resilience .....	31
Bandura’s (1986) Social Cognitive Theory .....	32

Related Literature.....	33
Adolescent Development.....	33
Multiple Dimensions of Identity.....	39
Risk Factors for Abusive Head Trauma.....	40
Signs and Symptoms.....	42
Outcomes.....	43
Prevention and Intervention Programs and Strategies.....	51
Qualitative Literature on Adolescents with Traumatic Brain Injury.....	57
Summary.....	59
<b>CHAPTER THREE: METHODS.....</b>	<b>61</b>
Overview.....	61
Design.....	61
Research Questions.....	63
Setting.....	63
Participants.....	64
Procedures.....	65
The Researcher's Role.....	66
Data Collection.....	68
Interviews.....	69
Observations.....	78
Document and Artifacts.....	79
Audiovisual Journal.....	80
Data Analysis.....	80



Trustworthiness.....	83
Credibility.....	84
Transferability.....	85
Ethical Considerations.....	85
Summary.....	86
CHAPTER FOUR: FINDINGS.....	87
Overview.....	87
Participants.....	87
Secondary Participants.....	88
Trudy.....	88
Results.....	104
Theme Development.....	104
Research Question Responses.....	104
Summary.....	128
CHAPTER FIVE: CONCLUSION.....	130
Overview.....	130
Summary of Findings.....	130
Discussion.....	132
Findings Related to Empirical Literature.....	132
Findings Related to Theoretical Literature.....	139
Implications.....	142
Theoretical Implications.....	142
Empirical Implications.....	143

Practical Implications.....	143
Delimitations and Limitations.....	144
Recommendations for Future Research .....	146
Summary .....	146
References.....	148
APPENDICES .....	158
Appendix A: IRB Approval Letter .....	158
Appendix B: Consent Form .....	159
Appendix C: Parent Consent & Child Assent Form .....	161
Appendix D: Observation Protocol.....	163
Appendix E: Email Permission to Use M. Chevignard Study .....	164
Appendix F: Reflective Journal .....	166
Appendix G: Hospital Photos .....	167
Appendix H: Medical Record I.....	168
Appendix I: Medical Record 2.....	169
Appendix J: First Individualized Education Plan Excerpt .....	170
Appendix K: Occupational Diploma Requirements .....	171
Appendix L: Trudy’s Baseball Photos .....	172
Appendix M: Project SEARCH Acceptance Letter.....	173
Appendix N: Excerpts from Trudy’s Final IEP .....	174
Appendix O: Enumeration Chart .....	175
Appendix P: Challenges Sub-Themes Enumeration Chart.....	176
Appendix Q: Resilience/Coping Mechanisms Sub-Themes Enumeration Chart .....	177

**List of Tables**

Table 1: Glasgow Outcome Scale.....	14
Table 2: Interview Questions Regarding Challenges and Resilience Mechanisms.....	78
Table 3: Secondary Participants and Their Relationship to Trudy.....	88

### **List of Abbreviations**

Abusive Head Trauma (AHT)

Assistive Technology (AT)

Cognitive support technology (CST)

Computerized Tomography Scan (CT Scan)

Individuals with Disabilities Education Improvement Act (IDEA)

Individualized Education Program (IEP)

Magnetic Resonance Imaging (MRI)

Shaken Baby Syndrome (SBS)

Traumatic Brain Injury (TBI)

## **CHAPTER ONE: INTRODUCTION**

### **Overview**

Abusive head trauma, also referred to as shaken baby syndrome in advocacy and prevention literature, is a nonaccidental brain injury that occurs in children under the age of two years old, and most frequently in children between the ages of 3-12 months old, due to violent shaking or impact to the head (Ali, Young, & Fallas, 2016; Barr, 2012; Chevignard & Lind, 2014). With an estimated annual incidence rate in the United States of 14-32 cases per 100,000 infants under the age of 12 months old, abusive head trauma is a growing healthcare concern that begs to be examined (Bechtel et al., 2011; Chevignard & Lind, 2014; Parrish, Baldwin-Johnson, Volz, & Goldsmith, 2013; Peterson et al., 2014; Stoll & Anderson, 2013; Xiang et al., 2013). While a plethora of quantitative studies have examined the outcomes associated with surviving an abusive head trauma, there are currently no qualitative studies giving a voice to survivors of an abusive head trauma. Therefore, the purpose of this qualitative, narrative study is to describe the life history of Trudy, an adolescent survivor of an abusive head trauma in the Southeastern United States. Chapter One provides a framework for the narrative, life history of an adolescent survivor of an abusive head trauma. This chapter includes a discussion of the background for the study, as well as the problem and purpose statements. The significance of the study and the research questions guiding the study are discussed and key terms are defined.

### **Background**

Of the 1.7 million people treated in emergency departments for traumatic brain injury annually in the United States, children aged 0 to 14 make up approximately 29% (Faul, Xu, Wald, & Coronado, 2010). The highest incidence of traumatic brain injury related emergency department visits, hospitalizations and deaths occur in males between the ages of 0 to 4-years-old

(Faul et al., 2010). Of the most severe traumatic brain injuries involving children, “abusive head trauma represents 17-56% of cases” (Chevignard & Lind, 2014, p. 549). Fatalities occur in “about 18-25% of babies who are shaken,” while an estimated “80% of survivors have significant lifelong brain injuries” (Barr, 2012, p. 17294). The diagnoses for children suffering an abusive head trauma range in severity from mild to severe, with the worst outcomes expected in the severe category. Though a small percentage (13%) of survivors have “good outcomes,” indicating an ability to attend general education classes, the Glasgow Outcome Scale indicates that most children who have suffered an abusive head trauma rank somewhere between “moderate” (25%) to “severe” (34%) in terms of disability level (Chevignard & Lind, 2014; Lind et al., 2016, p. 361). As indicated in Table 1, the Glasgow Outcome Scale reflects the variance in cognitive functioning and motor deficits for each category on the scale.

Table 1

*Glasgow Outcome Scale*

Scale Score	Category	Characteristics
1	Good outcome	Age-appropriate levels of cognitive functioning; School-aged functioning without special education
2	Moderate disability	Significant reduction in cognitive functioning; engaged in special education therapy; and/or motor deficits interfere with daily living
3	Severe disability	Deficient cognitive functioning; and/or severe motor deficits; requires substantial assistance with self-care skills
4	Persistent vegetative state	No evidence of verbal or nonverbal communication; unresponsive to commands
5	Death	

Note. Adapted from “Long-term outcome of abusive head trauma,” by M.P. Chevignard and K. Lind, 2014, *Pediatric Radiology*, 44, p.550. Used by permission.

Abusive head trauma is a form of inflicted brain injury, often resulting from violence in

the form of shaking, with or without impact to the head, of an infant under the age of two years old (Barr, 2012; Chevignard & Lind, 2014). With an annual incidence rate of 14-32 per 100,000 patients younger than 12 months of age treated in the United States and a mortality rate of 18-25% among those treated, abusive head trauma is a growing health concern, as both human and actual costs are burdensome and have long term negative impacts on the affected child, family and community resources, as well as the nation's healthcare system and school systems (Barr, 2012; Bechtel et al., 2011; Chevignard & Lind, 2014; Parrish et al., 2013; Peterson et al., 2014; Stoll & Anderson, 2013; Xiang et al., 2013).

Children suffering abusive head trauma present with a range of symptoms that make accurate diagnosis challenging for health care providers. In some cases, misdiagnoses occur, specifically when symptoms conflict with available clinical history of the affected child (Postema, Sieswerda-Hoogendoorn, Majoie, & van Rijn, 2014). However, many studies reveal a higher likelihood for the underrepresentation of the actual number of cases of abusive head trauma reported annually (Adamsbaum, Grabar, Mejean, & Rey-Salmon, 2010; Chevignard & Lind, 2014; Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Lind et al., 2016; Mok, Jones, Myerscough, Shah, & Minns, 2010; Parrish et al., 2013; Peterson et al., 2014; Simonnet et al., 2014; Stoll & Anderson, 2013; Xiang et al., 2013). Additionally, children who suffer an abusive head trauma face high rates of impairment in the neurological, cognitive and behavioral domains that affect them for the rest of their lives (Chevignard & Lind, 2014; Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Lind et al., 2016; Parrish et al., 2013; Peterson et al., 2014; Postema et al., 2014; Risen, Suskauer, DeMatt, Slomine, & Salorio, 2014; Simonnet et al., 2014; Stoll & Anderson, 2013; Xiang et al., 2013).

Many significant quantitative studies focus on abusive head trauma with the primary

research focus centered on providing a statistical background regarding prevalence (Díaz-Olavarrieta et al., 2011; Parrish et al., 2013; Xiang et al., 2013), outcomes (Chevignard & Lind, 2014; Lind et al., 2016; Risen et al., 2014; Vu, Babikan & Asarnow, 2011), risk factors (Adamsbaum et al., 2010; Díaz-Olavarrieta et al., 2011; Mok et al., 2010; Tanoue & Matsui, 2015), signs and symptoms (Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Postema et al., 2014), direct costs (Chevignard & Lind, 2014; Peterson et al., 2014; Stoll & Anderson, 2013) and prevention strategies (Bechtel et al., 2011; Simonnet et al., 2014; Stoll & Anderson, 2013). While the information garnered from these quantitative studies is essential, there are no qualitative studies providing insight into the social, emotional, academic, or physical challenges faced by survivors or the resilience mechanisms employed to survive with an abusive head trauma. The current study will allow the voice of an adolescent survivor to reveal the challenges she faces and the resilience mechanisms she employs to cope with living with an abusive head trauma.

Three primary theories form the theoretical framework of this study: Bronfenbrenner's (1979) ecology of human development, Ungar's (2012) theory of social-ecological resilience, and Bandura's (1986) social cognitive theory. Bronfenbrenner's (1979) ecology of human development emphasizes the relationship between individuals and their environments. The environment is divided into five separate systems, including the microsystem, mesosystem, exosystem, macrosystem and chronosystem, which all work together to influence the development of the individual (Bronfenbrenner, 1979). This theory informs the study regarding demographic risk factors that play a role in the occurrence of an abusive head trauma in young children.

Resilience is "the capacity and dynamic process of adaptively overcoming stress and



adversity” (Wu et al., 2013, p. 1). Influenced by Bronfenbrenner’s (1979) ecological systems theory, Ungar’s (2012) theory of social-ecological resilience will be utilized to inform the development of resilience in an adolescent survivor of an abusive head trauma, as resilience is “a quality of both individuals and their environments” (Ungar, Ghazinour & Richter, 2012, p. 361).

Bandura’s (1986) social cognitive theory highlights the connection between learning and the social context in which learning occurs. According to Bandura (1986), learning largely occurs through observation. Bandura (1986) posited that learning results from triadic reciprocal causation, which occurs through interactions among personal characteristics, behavioral patterns and the social environment. Five central concepts define how learning transpires: modeling, outcome expectancies, self-efficacy, goal setting and self-regulation (Bandura, 1986). Of these five concepts, Bandura stated that “none is more central” to gaining knowledge than self-efficacy (Benight & Bandura, 2004, p. 1131). In the current study, Bandura’s (1986) social cognitive theory provides the lens for investigating the role of self-efficacy in the development of resilience in an adolescent survivor of an abusive head trauma.

### **Situation to Self**

I have always been enamored with the concept of resilience, especially in young people. This admiration is the result of my own experiences with resilience. As a child, I lived in poverty with an abusive father until I was 10 years old. Neither of my parents attained a high school education, but I was certain I wanted a better life for myself. When my mother remarried, she and my step-father, who is a great dad, worked hard to take care of my brother and me. We may not have had all we wanted, but we had what we needed. My parents encouraged my brother and me to earn good grades, but they did not know how to help us with school work beyond middle school. So, I learned quickly that if I wanted to graduate from high school and go

to college, I needed to figure out how to do it on my own.

As a parent, I emphasize the need to be resilient to my children and as a public high school teacher, I emphasize the need for resilience to my students. Several years ago, I met a little girl who is a survivor of an abusive head trauma that occurred when she was an infant. I had a basic understanding of abusive head trauma, but I did not understand how something like this could happen, especially to this little girl. In my interactions with her, as she grew into an adolescent, she continued to be warm, friendly and full of joy and always ready to tell a good story. Over the years, the thought kept entering my mind that she is a great example of what it means to be resilient. As I got to know her more on a social level, I became curious about her experiences in coping with this diagnosis. In an effort to understand what she may have experienced, I began to try to find stories of other children who had experienced growing up after suffering an abusive head trauma and realized that no such stories exist. This gap in the literature is what motivated me to inquire into and tell this young woman's story.

Philosophical assumptions, such as ontological, epistemological and axiological influence qualitative research. Ontological assumptions "relate to the nature of reality and its characteristics" (Creswell, 2013, p. 20). My ontological assumption is that multiple realities exist, and I reported these as I collected stories from the primary participant, as well as secondary participants (Clandinin, 2013; Clandinin & Connelly, 2000; Creswell, 2013). Epistemological assumptions refer to the premise that "researchers attempt to get as close as possible to the participant being studied" (Creswell, 2013, p. 20). My epistemological assumption was that I would get as close to my primary participant as possible by conducting my research in the field and I believe that I accomplished this (Clandinin, 2013; Clandinin & Connelly, 2000; Creswell, 2013). Axiological assumptions acknowledge that "qualitative researchers make their values

known in a study” (Creswell, 2013, p. 20). The axiological assumption in this current study is that I admit that the stories told are not only a presentation of reality for the primary participant, but a reflection of my own voice (Clandinin, 2013; Clandinin & Connelly, 2000; Creswell, 2013; Riessman, 1993).

This study is also influenced by my Christian worldview, which is grounded in the belief that the Bible is the infallible Word of God and that my purpose is to love and serve God through my own words and deeds. Galatians 6:9 (ESV) states “and let us not grow weary of doing good, for in due season we will reap, if we do not give up.” As I allow my dependence on Christ to lead and guide this study, I pray diligently that the words that I have written will bring honor and glory to my God and King as I tell the story of one of His children.

Approaching this study through a paradigm of social constructivism, I am emphasizing “language as a primary conduit by which meaning is made” (Walker, 2015, p. 37). As a qualitative researcher, I acknowledge that a “constructivist worldview manifest[s]. . . as individuals describe their experiences” (Creswell, 2013, p. 25), which was accomplished through interviews with the primary participant, Trudy, as well as interviews with the secondary participants, who provided insight into Trudy’s challenges and triumphs. I was seeking to understand the experience of living with an abusive head trauma from the perspective “of someone who has lived it” (Walker, 2015, p. 37). Hence, the social constructivist paradigm fit well with a qualitative, narrative life history methodology and design.

### **Problem Statement**

Abusive head trauma, defined as “an extremely serious form of inflicted brain injury” which occurs as a result of “violent shaking, with or without impact, of an infant by an adult,” (Chevignard & Lind, 2014, p. 548) is a serious and growing healthcare concern in the United

States, with an estimated annual incidence rate of 14-32 cases per 100,000 infants younger than 12 months of age (Bechtel et al., 2011; Chevignard & Lind, 2014; Parrish et al., 2013; Peterson et al., 2014; Stoll & Anderson, 2013; Xiang et al., 2013). Heavily quantitative, the current literature reveals: the prevalence (Díaz-Olavarrieta et al., 2011; Parrish et al., 2013; Xiang et al., 2013), outcomes (Chevignard & Lind, 2014; Lind et al., 2016; Risen et al., 2014; Vu et al., 2011), risk factors (Adamsbaum et al., 2010; Díaz-Olavarrieta et al., 2011; Mok et al., 2010; Tanoue & Matsui, 2015), signs and symptoms (Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Postema et al., 2014), direct costs (Chevignard & Lind, 2014; Peterson et al., 2014; Stoll & Anderson, 2013) and prevention strategies (Bechtel et al., 2011; Simonnet et al., 2014; Stoll & Anderson, 2013). The abundance of quantitative studies on various aspects of abusive head trauma in the current literature points to a gap in the research, which is the scarcity in qualitative studies regarding this phenomenon. The problem is that there is currently no research describing the life story of an individual who has experienced and coped with an abusive head trauma.

### **Purpose Statement**

The purpose of this narrative study is to describe the life history of an adolescent survivor of an abusive head trauma in the Southeastern United States. Life history is defined as a first-hand account of “a series of events/actions, chronologically connected,” to convey understanding of a life (Creswell, 2013, p. 76). Abusive head trauma is a form of inflicted brain injury, most often occurring because of violence in the form of shaking or impact to the head of an infant under the age of two years old (Chevignard & Lind, 2014). The theories guiding this study are Bronfenbrenner’s (1979) ecology of human development as it focuses on the relationship between individuals and their environments, Ungar’s (2012) theory of social-ecological resilience as it explores the relationship between an individual’s resilience and their

environments, and Bandura's (1986) social cognitive theory as it emphasizes the importance of self-efficacy, as it relates to resilience, which in this study will be referred to as "the capacity and dynamic process of adaptively overcoming stress and adversity" (Wu et al., 2013, p. 1).

### **Significance of the Study**

While abusive head trauma is a growing health concern in the United States, the existing literature is overwhelmingly quantitative in nature. Abusive head trauma carries more significance than revealed through quantitative, statistical studies since this diagnosis affects children and their caregivers throughout the lifetime of the affected child. There are currently no qualitative studies revealing the human experience of surviving an abusive head trauma, indicating a critical gap in the literature. This study addresses the gap in the literature to make an original, empirical contribution as a qualitative study giving a voice to a survivor of an abusive head trauma.

A theoretical contribution was made as this study explored the influence of environment on a survivor of an abusive head trauma and her developed resilience, as well as the notion of self-efficacy as it relates to the survivor's lived experiences (Bandura, 1986; Bronfenbrenner, 1979; Ungar 2012). Until now, these theories have not yet been used to frame an inquiry on the development of resilience in an adolescent survivor of an abusive head trauma.

Finally, this study informs practice for parents, teachers, medical providers, counselors and others interacting with adolescent survivors of an abusive head trauma. Caregivers and practitioners will gain valuable insight into the challenges faced and the resilience mechanisms utilized by an adolescent survivor of an abusive head trauma. This information may spur further studies on coping mechanisms that could lead to the development of strategies to address the challenges faced by other survivors of an abusive head trauma, essentially improving their

quality of life. Additionally, this study may provide encouragement to the children and the families of children who experience an abusive head trauma.

### **Research Questions**

Research questions are an essential component of a sound qualitative study as they help to define the purpose of the study for both the researcher and the reader. While the central question provides insight into the broad intent of the study, sub-questions help to further specify the study's intent (Creswell, 2013). The central question guiding the current study is:

What are the lived experiences of an adolescent survivor of an abusive head trauma in the Southeastern United States?

The serious nature and growing concern for the increase in the number of cases of abusive head trauma occurring in the United States annually, as well as the heavily quantitative nature of previous studies focused on this diagnosis, indicate the need for scholarly qualitative research in this area (Bechtel et al., 2011; Chevignard & Lind, 2014; Parrish et al., 2013; Peterson et al., 2014; Stoll & Anderson, 2013; Xiang et al., 2013). Therefore, the current study will begin to fill the gap in the literature, as there are no studies telling the life history of an adolescent survivor of an abusive head trauma.

#### **Sub-Question 1: Challenges**

To help specify the intent of the current study, the first sub-question is:

What challenges does an adolescent survivor of an abusive head trauma face?

Previous quantitative research studies indicate that survivors of abusive head trauma face neurological, cognitive, and behavioral challenges that range from severe to mild impairments throughout the lifetime of the survivor (Chevignard & Lind, 2014; Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Lind et al., 2016; Parrish et al., 2013; Peterson et al., 2014; Postema et al.,

2014; Risen et al., 2014; Simonnet et al., 2014; Stoll & Anderson, 2013; Xiang et al., 2013). In the current study, I am seeking to identify specific challenges that my participant has faced throughout her lifetime, as well as current challenges that she faces as an adolescent survivor of an abusive head trauma.

### **Sub-Question 2: Resilience Mechanisms**

To be more specific, a second sub-question clarifies the intent of the current study further:

What resilience mechanisms does an adolescent survivor employ to cope with living with an abusive head trauma?

Recent research indicates that while resilience has become the focus of many studies of individuals and groups who have experienced some form of trauma or adversity, there is no universal definition of the term (Aburn, Gott, & Hoare, 2015). A recent metacognitive examination of the concept of resilience indicates that resilience is “the capacity and dynamic process of adaptively overcoming stress and adversity” (Wu et al., 2013, p. 1). This definition will be applied to the current study to identify the mechanisms, that is, the characteristics (Fletcher & Sarkar, 2013) utilized by the participant to allow her to cope with living with an abusive head trauma.

### **Sub-Question 3: Advice**

A third and final sub-question is:

What advice would an adolescent survivor give to someone who has experienced an abusive head trauma?

Approaching this study from a social constructivist paradigm, it is essential to “understand the world of lived experience from those who have lived it” (Walker, 2015, p. 37). Allowing Trudy

the opportunity to pass along advice to others who have experienced an abusive head trauma will reveal a deeper layer of how she has experienced living with this trauma.

### **Definitions**

Relevant terms for the study are listed and defined below.

1. *Abusive head trauma (AHT)* – Abusive head trauma is a form of inflicted brain injury, most often occurring as a result of violence in the form of shaking or impact to the head of an infant under the age of two years old (Chevignard & Lind, 2014; Parks, Annett, Hill, & Karch 2012).
2. *Assistive technology (AT)* – An assistive technology is “any item or equipment that is used to improve or maintain an individual’s independence and/or functioning” (Oliver, Montero, Fernandez-Cabellero, Gonzalez, & Molina, 2015, p. 370).
3. *Cognitive support technology (CST)* – A cognitive support technology is a “device or service intended to reduce the impact of disability for individuals with functional deficits in cognition” (Chu, Brown, Harniss, Kautz, & Johnson, 2014, p. 280).
4. *Education for All Handicapped Children Act (1975)* – The Education for All Handicapped Children Act (1975), P.L. 94-142, was passed by the United States Congress to “support states and localities in protecting the rights of, meeting the individual needs of, and improving results for infants, toddlers, children, and youths with disabilities and their families” (U.S. Department of Education, 2010, p.1).
5. *Glasgow Outcome Scale* – The Glasgow Outcome Scale is a five-point score, modified for use with children, following brain injury to indicate outcome severity. Outcomes are rated as follows: (1) “good outcome,” (2) “moderate disability,” (3) “severe disability,” (4) “persistent vegetative state,” and (5) “death” (Chevignard & Lind, 2014, p. 550).



6. *Individualized Education Program* – An Individualized Education Program is defined as “a written statement for each child with a disability that is developed, reviewed, and revised on an annual basis” that must include: “(1) a statement of the child’s present levels of academic achievement and functional performance, (2) measurable annual goals including academic and functional, (3) a description of how progress towards meeting the annual goals will be measured and when periodic reports will be provided, (4) a statement of the special education and related services and supplementary aids and services, based on peer-reviewed research and to the extent practicable to be provided to the child, on behalf of the child, and a statement of program modifications or supports for school personnel that will be provided to enable the child, (5) an explanation of the extent, if any, to which the child will not participate with nondisabled peers in the regular class, (6) a statement of any individual appropriate accommodations that are necessary to measure the academic achievement and functional performance of the child on State and districtwide assessments, and (7) the projected date for beginning of the services and modifications and anticipated frequency, location and duration of those services and modifications” [34 CFR 300.320].
7. *Individuals with Disabilities Education Improvement Act (2004)* – The Individuals with Disabilities Education Improvement Act (2004) was originally passed by the United States Congress in 1990 to amend and replace the Education of All Handicapped Children Act (1975) and was reauthorized in 2004. Its mandates extend those of the Education of All Handicapped Children Act (1975) and include post-secondary transition planning for eligible students (U.S. Department of Education, 2010).

8. *Life history* – Life history is the “unfolding of an individual’s lived experiences over time,” (Schwandt, 2015, p. 19) expressed as a narrative resulting from an “analysis of social, historical, political, and economic contexts” (Gough, 2008, p. 484).
9. *Resilience* - Resilience is “the capacity and dynamic process of adaptively overcoming stress and adversity” (Wu et al., 2013, p. 1).
10. *Resilience mechanism* – Resilience mechanisms are the characteristics of individuals that allow them to thrive while facing adversity (Fletcher & Sarkar, 2013).
11. *Traumatic Brain Injury (TBI)* – According to the Individuals with Disabilities Education Improvement Act (2004), traumatic brain injury is “an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. Traumatic brain injury applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. Traumatic brain injury does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma.” [Sec. 300.8 (c) (12)]

### **Summary**

Abusive head trauma is a growing concern in the United States, as many children, their families and society-at-large are affected by the devastating outcomes, including long-term negative impacts on the child, and costly consequences to healthcare and school systems (Bechtel et al., 2011; Chevignard & Lind, 2014; Parrish et al., 2013; Peterson et al., 2014; Stoll & Anderson, 2013; Xiang et al., 2013). Survivors of an abusive head trauma experience

neurological, cognitive, and behavioral challenges that impact their education. While quantitative research reveals the statistical background of this diagnosis, the problem is that there is currently no research telling the life story of an individual who has experienced and coped with an abusive head trauma. The purpose of the current study is to fill the gap in the literature by narrating the life history of an adolescent survivor of abusive head trauma, to gain a first-hand account of the challenges faced and the resilience mechanisms employed to cope with those challenges. Chapter One provides a framework for the current research study including background, situation to self, problem statement, purpose statement, and the significance of the study. Additionally, research questions are introduced and key terms for the study are defined.

## CHAPTER TWO: LITERATURE REVIEW

### Overview

In the United States, 1.7 million people are treated for traumatic brain injuries annually (Faul et al., 2010). Of those treated in emergency departments, children aged 0 to 14 make up roughly half a million cases yearly (Faul et al., 2010). Males between the ages of 0 to 4-years-old have the highest rates of traumatic brain injury related emergency department visits, hospitalizations and deaths (Faul et al., 2010). Of those 500,000 cases involving children, “17-56%” of the most severe traumatic brain injuries are the result of an abusive head trauma (Chevignard & Lind, 2014, p. 549). First identified by pediatric neurosurgeon, Norman Guthkelch in 1971, this form of abuse was known as Shaken Baby Syndrome (SBS), due to the belief that infants and toddlers experienced subdural hemorrhages as a result of being shaken by an adult perpetrator (Barr, 2012). Recently, the American Academy of Pediatrics has recommended that the term “shaken baby syndrome” be used for advocacy and prevention, while the term “abusive head trauma” (AHT) be used for medical and legal purposes since trauma can occur with or without impact to an infant or toddler’s head (Barr, 2012). For the purposes of this study, abusive head trauma (AHT) refers to a form of nonaccidental brain injury, occurring because of violence due to shaking or impact to the head of an infant between the ages of 0 to 2-years old (Chevignard & Lind, 2014; Parks et al., 2012). With an annual incidence rate of 14-32 per 100,000 patients younger than 12 months of age treated in the United States, a mortality rate of 18%-25% among those treated, as well as high rates of long-term brain injury for 80% of survivors, abusive head trauma is a growing health concern, as both human and actual costs are burdensome and have long term negative impacts on the affected child, family and community resources, as well as the nation’s healthcare system and school systems (Barr, 2012; Bechtel et

al., 2011; Chevignard & Lind, 2014; Parrish et al., 2013; Peterson et al., 2014; Stoll & Anderson, 2013; Xiang et al., 2013).

Children suffering abusive head trauma present with a range of symptoms that make accurate diagnosis challenging for health care providers, in addition to facing high rates of impairment in the neurological, cognitive and behavioral domains that affect them for the rest of their lives (Adamsbaum et al., 2010; Chevignard & Lind, 2014; Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Lind et al., 2016; Mok et al., 2010; Parrish et al., 2013; Peterson et al., 2014; Postema et al., 2014; Risen et al., 2014; Simonnet et al., 2014; Stoll & Anderson, 2013; Xiang et al., 2013). This chapter includes a discussion of Bronfenbrenner's (1979) ecology of human development, Ungar's (2012) theory of social-ecological resilience, and Bandura's (1986) social cognitive theory that forms the theoretical framework for the study. Following this, the related literature covers such topics as adolescent development and multiple dimensions of identity that provides insight into the current knowledge base regarding risk factors, signs and symptoms, outcomes, and prevention and intervention strategies related to abusive head trauma, as well as a discussion of the existing qualitative literature related to traumatic brain injury in adolescents, and a need for a qualitative, narrative study to strengthen understanding of the challenges associated with living with this diagnosis. To build a framework, I begin with a discussion of the theories that inform this study.

### **Theoretical Framework**

It is important to look at abusive head trauma through a theoretical lens to understand how the research questions regarding this study have been formulated, how the questions were answered and information evaluated, as well as to ground the research study in scholarly work (Creswell, 2013). The theories guiding this study are Bronfenbrenner's (1979) ecology of

human development as it focuses on the relationship between individuals and their environments, Ungar's (2012) theory of social-ecological resilience as it explores the relationship of individual's resilience and their environments and Bandura's (1986) social cognitive theory as it emphasizes the importance of self-efficacy, as it relates to resilience.

### **Bronfenbrenner's (1979) Ecology of Human Development**

Urie Bronfenbrenner's (1979) ecology of human development encompasses the individual, the environment and interaction between the two. Bronfenbrenner conceptualized individuals as active human beings who have an evolving relationship with environments in which they live. The environment is divided into a system of five different levels: the microsystem, mesosystem, exosystem, macrosystem and chronosystem (Bronfenbrenner, 1979). The microsystem is one's direct environment (e.g., family, home, school), while the mesosystem consists of relationships between microsystems (e.g., between home and school) (Bronfenbrenner, 1979). The exosystem is the setting in which there is a link between the context where the person does not have any active role, and the context where the person is actively participating and the macrosystem is an individual's culture (Bronfenbrenner, 1979). Finally, the chronosystem is the series of transitions and shifts that occur in an individual's lifespan (Bronfenbrenner, 1979). Clandinin (2013) viewed experience as "a changing stream that is characterized by continuous interaction of human thought with our personal, social, and material environment" (p. 39). Bronfenbrenner's (1979) ecological systems theory helps to inform an understanding of the role that demographic risk factors play in the occurrence of abusive head trauma, as well how resilience develops in an adolescent survivor of abusive head trauma.

### **Ungar's (2012) Theory of Social-Ecological Resilience**

Ungar's (2012) theory of social-ecological resilience is based on Bronfenbrenner's (1979) bio-social-ecological model of human development. Both models point to resilience as a multi-systemic process, combining bio-, micro-, meso-, exo-, macro-, and chrono-systemic processes to gain an in-depth understanding of overall resilience and the factors that lead to resilience in human beings. Ungar's (2012) social-ecological model defines resilience as "a quality of both individuals and their environments," meaning that resilience must be studied through the individual's interaction within various environments (Ungar, Ghazinour, & Richter, 2012, p. 361). Clandinin and Rosiek (2007), believed that the stories that people live and tell:

are the result of a confluence of social influences on a person's inner life, social influences on their environment, and their unique personal history. These stories are often treated as the epiphenomenal to social inquiry- reflections of important social realities but not realities themselves. (p. 41)

In other words, an individual's resilience cannot be understood by examining the traits of the individual in isolation, but must be studied in terms of the environments (e.g., home, school, religious organizations, community, culture) with which the individual interacts. The social-ecological model can be understood in terms of three principle concepts:

Equifinality (many good means to many good ends), differential impact (different protective processes influence resilience differently depending on the individual's exposure to risk) and contextual and cultural moderation (protective processes are valued and made available differently in different contexts and cultures). (Ungar et al., 2012, p. 361)

This study will examine the resilience of an adolescent survivor of an abusive head trauma in the context of these three principle concepts and within the social-ecological systems model.

### **Bandura's (1986) Social Cognitive Theory**

Social cognitive theory (Bandura, 1986) posits that learning occurs in social contexts and much of what is learned is gained through observation. Knowledge can be gained as a result of triadic reciprocal causation, through interactions among personal characteristics, behavioral patterns and the social environment (Bandura, 1986). Three assumptions are made by the social cognitive theory: (a) learning happens in a bidirectional, reciprocal fashion, (b) people have the ability to influence their own learning, and (c) learning can occur without immediate changes in behavior (Bandura, 1986). This theory is further explained through examination of five central concepts: modeling, outcome expectancies, self-efficacy, goal setting and self-regulation (Bandura, 1986). According to Bandura, "among the mechanisms of human agency, none is more central or persuasive than people's beliefs in their efficacy to manage their own functioning and to exercise control over events that affect their lives" (Benight & Bandura, 2004, p. 1131). Self-efficacy aids in understanding resilience in survivors of traumatic events, such as the focus of this study, an adolescent survivor of an abusive head trauma.

Self-efficacy theory (Bandura, 1986) is rooted in the social cognitive theory. This theory posits that interaction exist between social, cognitive, behavioral and psychological factors to influence motivation (Bandura, 1986). Self-efficacy theory states that various experiences of efficacy and consequences of efficacy judgments interact to influence behavior (Driver, 2006). Concerning self-efficacy theory and brain injuries, survivors who exhibit higher levels of self-efficacy demonstrate an ability to better adapt to their environments and attain new life goals



following injury (Brands, Stapert, Köhler, Wade, & van Heugten, 2015; Driver, 2006). Self-efficacy theory provides a clear lens for studying resilience in a survivor of abusive head trauma.

### **Related Literature**

Many quantitative studies have been conducted regarding various aspects of abusive head trauma, including risk factors, signs and symptoms, outcomes, and prevention and intervention strategies, presented in this section. While no qualitative studies were identified that focused on the experience of adolescent survivors of an abusive head trauma, there are a small number focused on the experiences of adolescent survivors of traumatic brain injury. The findings of these studies are presented following the discussion of the quantitative literature on abusive head trauma. This section begins with an examination of human development through adolescence.

### **Adolescent Development**

To further gain insight into the cognitive and behavioral challenges faced by an adolescent survivor of an abusive head trauma that occurred as an infant, it is critical to examine the stages of human development from infancy through adolescence. This examination will provide a basis for analysis of this study's findings in light of the stages of development and produce a clearer picture of the effects of suffering an abusive head trauma on the typical arc of development. This section includes a discussion of the stages of human development from infancy through adolescence as proposed by Jean Piaget, Erik Erikson, and Jerome Bruner.

**Piaget's (1936/1953) stages of cognitive development.** In his theory of cognitive development, Jean Piaget (1936/1953) asserted that children have a natural ability to construct meaning about the world around them. Piaget (1952) believed that children build their knowledge of the world using schema, which he defined as "a cohesive, repeatable action sequence possessing component actions that are tightly interconnected and governed by a core

meaning” (p. 7). In other words, schema act as a cognitive framework on which children build their capacity to understand the world around them. These schema act as shortcuts for understanding new experiences and information by fitting that information into categories. Piaget (1952) supposed that all individuals seek a state of equilibrium, achieving a balance between existing and new experiences and information. To achieve equilibrium, individuals adapt new information and experiences through assimilation or accommodation (Piaget, 1952). Assimilation allows the use of existing schema to cope with new experiences or situations. For example, a child learns that dogs are four-legged, furry animals, so when the child’s family gets a bulldog as a pet and the child sees a cocker spaniel on a walk with his family, the child refers to both animals as dogs. Accommodation, on the other hand, occurs when existing schema are modified or new schema are formed to cope with new experiences or knowledge. When the child in the previous example sees a cat for the first time, he may refer to it as a dog, until his family tells him that this is a cat. The child then adjusts his knowledge to include only certain types of four-legged, furry animals in the category of dogs. The child has accommodated this new knowledge to fit his existing schema.

In addition to explaining how individuals construct knowledge, Piaget (1952) contemplated that cognitive development occurs in four, ordered stages: (a) sensorimotor, (b) pre-operational, (c) concrete operational, and (d) formal operational. During the sensorimotor stage, which occurs from birth through 2 years of age, children understand the world through their senses and actions. While knowledge of the world is very limited, the main achievement during this stage is object permanence, the realization that an object still exists even when the object cannot be seen. In the pre-operational stage, occurring from 2-7 years of age, children begin to understand the world through language and mental images. Children in this stage engage in

symbolic or pretend play, though their thinking is largely ego-centric and non-logical. Following the pre-operational stage is the concrete operational stage, which occurs for most children between the ages of 7-11 years old. During this stage, ego-centrism begins to diminish as children gain the ability to use inductive reasoning. Children in this stage also develop an understanding of conservation, the concept that quantity remains the same, though appearance may change. For example, children understand that if a sandwich is cut in half, it is still the same amount as if the sandwich had not been cut in half. The fourth and final stage of cognitive development is the formal operational stage, which begins in early adolescence and continues into adulthood. Early in the formal operational stage, there is a brief return to egocentrism as a child enters adolescence. Individuals gain the ability to think abstractly and to use deductive reasoning, which shows up through creative solutions to solving problems. Knowledge is demonstrated through hypothetical thinking, scientific reasoning, and systematic planning. Metacognition, the ability to think about one's thoughts, also develops during this stage, however, Piaget (1952) admitted that some individuals do not attain the formal operational stage until well into adulthood.

**Erikson's (1959/1980) stages of psychosocial development.** Though Erik Erikson was influenced early on by his teacher, Sigmund Freud, unlike Freud or Piaget, Erikson emphasized the role of culture and society in the development of personality throughout an individual's lifespan. Erikson (1950) believed that individuals experience a psychosocial crisis during each of the stages of development and that the way in which those crises are resolved results in either a positive or negative impact on the development of personality as one progresses through life. In his *Eight Stages of Man*, Erikson (1950) argued that psychosocial development occurs through the positive resolution of the following eight crises: (a) trust v. mistrust, (b) autonomy v. shame

and doubt, (c) initiative v. guilt, (d) industry v. inferiority, (e) identity v. role confusion, (f) intimacy v. isolation, (g) generativity v. stagnation, and (h) ego integrity v. despair. Of these eight stages, the last three occur in adulthood and the first five focus on the period of infancy through adolescence. Since this study is concerned with the life history of an adolescent survivor of an abusive head trauma, only the first five stages have been included in this discussion.

The first crisis, trust v. mistrust occurs in infancy, where positive resolution is based on the infant's experience that their basic needs for survival will be met, resulting in the development of a sense of hope, security and trust, which will be carried into future relationships. Negative resolution at this stage based on inconsistency in the infant's experience with having their basic needs met, will lead to anxiety, insecurity and mistrust in future relationships. The second crisis, autonomy v. shame and doubt occurs during the toddler years between ages 18 months to 3 years old. During this stage, toddlers experience a growing sense of autonomy as they can make their own choices, such as which toys to play with or even successfully toilet training. Positive resolution at this stage, which is based on encouragement and support from caregivers, results in increased self-confidence and security in their abilities to exercise independence. Negative resolution, based on criticism and overly controlling caregivers results in toddlers becoming overly dependent upon others, as well as low self-esteem due to feelings of inability and even shame over a lack of self-control.

Crisis three, initiative v. guilt occurs in early childhood, between the ages of 3-5 years old. At this stage, children begin to ask a lot of questions as their curiosity takes off, as well as to assert themselves, as they engage in actively playing with other children. Positive resolution allows children to develop a sense of initiative and to feel secure in their ability to make decisions, as their curiosity is encouraged and supported by caregivers, teachers and friends.

Negative resolution results from squelched initiative and inappropriate responses to a child's inquisitiveness, which can lead children to develop a sense of guilt, which could later inhibit creativity and interaction with others. Industry v. inferiority is the fourth crisis and occurs during elementary and middle school between the ages of 5-12 years old. During this stage, children feel a need to learn to do things well and to perform at a level that is acceptable to their peers and others, especially concerning education and extracurricular activities, such as sports. Positive resolution at this stage, based on encouragement and reinforcement, leads to high levels of competence (industry) and increased self-esteem, as well as pride and confidence in a child's abilities to perform at high levels. Negative resolution at this stage can lead to a sense of inferiority, where children doubt their abilities to the point that they cannot achieve their goals.

Erikson (1963) stated that "the adolescent mind is essentially a mind or moratorium, a psychosocial stage between childhood and adulthood, and between the morality learned by the child and the ethics to be developed by the adult" (p. 245). The fifth crisis, encountered in adolescence between the ages of 12-18 years old, is identity v. role confusion. During this stage, adolescents begin to focus on the future as they transition from childhood to adulthood, exploring personal values, beliefs and goals and examining what they want to do with their lives and who they want to be. Adolescents also experience a longing to belong or fit in, while simultaneously coping with issues surrounding body image, as they physically mature into adulthood. Positive resolution at this stage results in the development of a healthy identity, as well as fidelity, the ability to live by societal standards and loyalty to others. Negative resolution may cause adolescents to feel unsure of themselves or their place in the world, leading to role confusion or identity crisis, which can result in unhappiness and lack of fulfillment.

**Bruner's (1966) cognitive development theory.** Jerome Bruner's work is often compared with that of Piaget since they both advocated a constructivist position regarding how children learn. Unlike Piaget (1952), who suggested that the complexity of subject material should align to the child's cognitive stage of development, Bruner (1960) believed that "any subject can be taught effectively in some intellectually honest form to any child at any stage of development" (p. 33). To accomplish this task, Bruner (1960) proposed a spiral curriculum, in which complex ideas would initially be taught in a simplified form and gradually increase in difficulty, leading children to eventually solve problems on their own. Rather than basing instruction on rote memorization, Bruner (1960) advocated that the aim of education should be the creation of autonomous learners, capable of solving complex problems by inventing new ways to do so. Bruner (1966) presented three modes of representation regarding cognitive development: (a) enactive representation, (b) iconic representation, and (c) symbolic representation.

Rather than these stages following a chronological progression, in which one stage must be attained before moving on to the next, as Piaget's (1952) stages of cognitive development indicate, Bruner's (1966) three modes of representation are integrated as one progresses through each stage. The enactive stage, also known as the concrete stage, allows for the representation of knowledge through actions, which are stored as muscle memory. For example, a child learning the value of money may be given paper money or plastic coins to count with while learning to add or subtract. Even though this stage can occur in young infants, adults also express knowledge through muscle memory, such as riding a bicycle or playing a musical instrument after a time away from those activities. In the iconic stage, also known as the pictorial stage, knowledge is stored in the form of images or mental pictures so an illustration or diagram helps

us to make sense of new knowledge, rather than using words alone. For example, when children are learning directions, providing a picture of what “left” and “right” look like allows them to commit the visual to memory or when adults are assembling a child’s toy, examining an illustration of the assembled object may be easier to comprehend than the written instructions alone. In the symbolic stage, also known as the abstract stage, knowledge is expressed in the form of words or symbols, which are flexible and can be manipulated, ordered and classified. For example, a teacher writes the following math problem on the board for her students to solve: “ $2 + 3 =$ ” and expects the students to know what to do. In the same vein as Lev Vygotsky (1978), Bruner saw development as a continuous process and emphasized the importance of language in symbolic representation as being critical for cognitive development. Just as it is critical to understand the arc of typical human development through adolescence, it is equally essential to examine the construction of individual and social identity as a basis for this study’s findings.

### **Multiple Dimensions of Identity**

As discussed in the previous section on adolescent development, the ways in which children progress and are allowed to progress through the stages of development will impact the construction of both individual and social identity. Abes, Jones and McEwan (2007) argued that identity is “socially, historically, politically, and culturally constructed” at both levels (p. 1). In one study by Jones and McEwen (2000), individual identity was defined as a core sense of self that is generally not characterized by external attributes. Participants in that study characterized their individual identities as “intelligent, kind, a good friend, compassionate, and independent,” deliberately avoiding the use of physical characteristics (Jones & McEwan, 2000, p. 408). It is important to note that “influences of sociocultural conditions, family background, and current

experiences cannot be underestimated in understanding how participants constructed and experienced their identities” (Jones & McEwan, 2000, p. 410). Whereas individual identity involves a core sense of self, social identity, who we are to others, generally includes more external descriptors or labels (white, female, heterosexual, middle-class, etc.). Participants expressed a desire “to be understood as they understood themselves,” with complex, intersecting identities rather than being confined by a singular attribute of their identities (Jones & McEwan, 2000, p. 412). Abes, Jones and McEwan (2007) argued the significance of the addition of the role of meaning-making in the reconceptualized model of multiple dimensions of identity to see others:

as they see themselves by understanding not only what they perceive their identity to be, but also how they make meaning of their identity dimensions as they do, how they come to perceive identity dimensions as salient or relatively unimportant, and to what degree they understand their social identities as integrated or distinct. (p. 19)

Therefore, individual and social identities are complex, intersecting structures through which we and others make sense of our life experiences. Now that a basis for analysis of the study’s findings has been presented, I will discuss the risk factors that have been identified for the possible occurrence of an abusive head trauma for infants.

### **Risk Factors for Abusive Head Trauma**

Risk factors for the occurrence of abusive head trauma have been a major focus of several quantitative studies in the past, as there is a drive to identify the causes that lead to this trauma and place young children at risk (Adamsbaum et al., 2012; Bechtel et al., 2011; Chevignard & Lind, 2014, Díaz-Olavarrieta et al., 2011; Mok et al., 2010; Kadom et al., 2014; Parrish et al., 2013; Postema et al., 2014; Stoll & Anderson, 2013; Tanoue & Matsui, 2015;



Xiang et al., 2013). First, the main trigger seems to be inconsolable crying by the infant or child at risk and the lack of caregiver knowledge as to how to effectively manage this behavior in small children (Barr, 2012; Chevignard & Lind, 2014, Díaz-Olavarrieta et al., 2011; Mok et al., 2010; Parrish et al., 2013; Stoll & Anderson, 2013; Tanoue & Matsui, 2015; Xiang et al., 2013). Several quantitative studies indicate that caregivers resort to shaking an inconsolable infant to calm or discipline the infant (Adamsbaum et al., 2010; Barr, 2009; Barr, 2012). Barr (2012) clarified the danger of shaking versus other forms of child abuse with this explanation:

On the one hand, the caregiver who slaps an infant experiences a stinging of the hand that might indicate he or she is acting in an inappropriate manner or has lost control, whereas shaking does not. Nor does it leave an external mark on the infant. On the other hand, an infant who is shaken typically stops crying due to having experienced a concussion-like brain injury, whereas a slap, hit, or throw against a hard object results in increased crying. (p. 17296)

This quieting effect leads to repeated instances of shaking by the caregiver in response to inconsolable crying episodes by the infant in the future. One study, based on the confessions of 29 perpetrators, revealed that shaking was repeated in 55% of AHT cases, ranging from 2-30 times, and occurring daily for weeks at a time because shaking the baby stopped the inconsolable crying in all cases and “he or she goes to sleep after being shaken” (Adamsbaum et al., 2010, p. 553).

While many victims of abusive head trauma are males under the age of two years old, with peak age around three months old, most perpetrators in cases involving abusive head trauma are also males, who may or may not be the biological father or even a relative of the child, but who live in the home (Adamsbaum et al., 2010; Barr, 2012; Bechtel et al., 2011; Díaz-

Olavarrieta et al., 2011; Kadom et al., 2014; Parrish et al., 2013; Postema et al., 2014; Stoll & Anderson, 2013). Other demographic factors that increase the risk of abusive head trauma for children include low parental socioeconomic status, unintended pregnancy, parental alcoholism, young age of the infant, young ( $\leq 20$ ) and unwed mothers with less than 12 years of education, and the presence of domestic violence (Adamsbaum et al., 2010; Bechtel et al., 2011; Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Parrish et al., 2013; Postema et al., 2014; Stoll & Anderson, 2013, Tanoue & Matsui, 2015; Xiang et al., 2013).

### **Signs and Symptoms**

A major challenge for the first responding medical care team in diagnosing abusive head trauma is the fact that children present with various signs and symptoms and in varying degrees of distress, all of which do not immediately indicate a diagnosis of abusive head trauma. The most telling symptom is generally thought to be the presence of a subdural hematoma, a life-threatening condition in which a pool of blood develops between the brain and its outer covering (Adamsbaum et al., 2010; Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Postema et al., 2014; Stoll & Anderson, 2013). The presence of a subdural hematoma is generally detected through the use of a Computerized Tomography (CT) scan or Magnetic Resonance Imaging (MRI), however, there is some discrepancy regarding the accuracy of diagnosis in utilizing these images in isolation, in that even experienced radiologists are not very confident in their ability to date the injury sufficiently enough to diagnose an abusive head trauma solely based on the presence of a subdural hematoma (Kadom et al., 2014; Postema et al., 2014). Therefore, to make a more accurate diagnosis, the medical care team must examine the child for other indicators of an abusive head trauma, including coma, seizures, retinal hemorrhages, cranial fracture, cerebral edema (accumulation of fluid in the brain) and atrophy, cervical injury, bruising in various stages

of healing, and other fractures in various stages of healing, often detected in as many as 30-70% of cases (Adamsbaum et al., 2010; Barr, 2012; Chevignard & Lind, 2014; Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Postema et al., 2014; Stoll & Anderson, 2013). Without a thorough examination of the child, the medical care team could misdiagnose an accident as child abuse resulting in “severe social and emotional problems for the involved child and parents/caregivers” (Postema et al., 2014, p. 350) or worse, a misdiagnosis of abusive head trauma as an accidental injury could occur, resulting in possible further injury to the child (Adamsbaum et al., 2010). One study revealed that “31% of cases were ‘missed’ on first presentation to health care facilities and that 28% of the missed cases were repeat injuries following the original missed diagnosis” (Barr, 2012, p. 17296).

### **Outcomes**

Children and infants diagnosed with abusive head trauma generally have poor outcomes and tend to have high rates of impairment across many domains including neurological, cognitive, and behavioral (Chevignard & Lind, 2014; Lind et al., 2016; Risen et al., 2014; Xiang et al., 2013). These impairments often cause delays and can have “devastating long term consequences of everyday functioning, social and academic areas, vocational outcome and participation in society and community integration” (Chevignard & Lind, 2014, p. 549).

**Short-term outcomes.** Children and infants diagnosed with abusive head trauma tend to suffer high mortality and morbidity rates (20-25%) at the onset (Chevignard & Lind, 2014). A high rate of impairment is also a factor in worse outcomes for these children, partially due to “initial delay in receiving care, as many children’s conditions only become recognized when they have respiratory distress or seizures or are unconscious” (Chevignard & Lind, 2014, p. 550). This delay in care also results in delayed identification of deficits, which are manifested as the

child attempts to grapple with social and cognitive situations not present at such a young age (Chevignard & Lind, 2014; Lind et al., 2016; Risen et al., 2014; Xiang et al., 2013).

**Long term outcomes.** In addition to the appearance of developmental delays, children diagnosed with abusive head trauma experience long-term neurological, cognitive, and behavioral deficits. These deficits have far reaching effects on the lives of the children who experience them from the modifications that must occur in their educational environments to the impact on their futures beyond school age. The monetary costs that are incurred as the result of lifetime care and assistive technology needs are overwhelming, placing a hefty financial burden on the families of children who suffer an abusive head trauma. It is essential to grasp the weight of the challenges that result from such abuse.

**Neurological challenges.** Children who suffer an abusive head trauma experience a high rate of impairment in the form of delayed psychomotor and motor deficits (45%) including: hypotonia (low muscle tone), spastic hemiplegia or quadriplegia (paralysis), ataxia (impaired balance or coordination), dystonia (involuntary muscle contractions that cause repetitive or twisting movements), cranial nerve abnormalities, as well as impaired walking, gross and fine motor functions (Chevignard & Lind, 2014; Lind et al., 2016). These impairments are often accompanied by hydrocephalus (build-up of fluid in deep within brain cavities), post-traumatic epilepsy and post-traumatic seizures (Chevignard & Lind, 2014; Lind et al., 2016; Stoll & Anderson, 2013). Another neurological challenge, which often occurs, is cerebral palsy (Chevignard & Lind, 2014; Lind et al., 2016; Stoll & Anderson, 2013). Additionally, sensory deficits appear in the form of deafness (from damage to the inner ear or damage to the nerve that runs from ear to brain), as well as long-term visual impairment and blindness including: cortical blindness (total or partial vision loss), loss of visual acuity, visual field defects, visual agnosia

(one can see but cannot recognize or interpret visual information), and abnormal extraocular movements with heterotopia (drifting eye movements) (Chevignard & Lind, 2014; Lind et al., 2016; Stoll & Anderson, 2013). A “high proportion of patients (36%) suffer severe neurological disabilities requiring significant long-term nursing and caregiver support in the community” (Chevignard & Lind, 2014, p. 553).

***Cognitive challenges.*** In regard to cognitive challenges, children diagnosed as suffering an abusive head trauma may experience speech and language deficits, which appear as impaired ability in comprehension and verbal fluency (Chevignard & Lind, 2014; Lind et al., 2016; Stoll & Anderson, 2013). These children often incur cognitive deficits, which manifest as impairments in visual information processing, visuo-motor integration and social skills (Chevignard & Lind, 2014; Stoll & Anderson, 2013). These “visual deficits increase developmental delays, learning difficulties and social integration” (Chevignard & Lind, 2014, p. 553), which often become apparent as learning disabilities are identified when children enter and experience learning at school. Children who have experienced an abusive head trauma exhibit “significant impairment in divided attention, working memory, and various aspects of executive functioning, such as reasoning, mental organization/planning, and mental alternation and inhibition, with a negative impact on intellectual ability and memory and slower execution time” (Chevignard & Lind, 2014, p. 554). Clearly, there is a “need to monitor cognitive development closely, over prolonged periods of time, including executive skills, since the frontal regions only reach maturity at the end of adolescence” (Chevignard & Lind, 2014, p. 554).

***Behavioral challenges.*** Behavioral challenges appear in many forms for children who have suffered an abusive head trauma: “agitation, aggression, severe temper tantrums, rage outbursts, inhibition or initiation deficits or autism spectrum disorders,” as well as “self-injurious

and self-stimulatory behaviors such as head banging, eye poking and biting, impulsivity, marked attention problems and ritualistic behaviors (in older children)” (Chevignard & Lind, 2014, p. 554). In addition to these behavioral challenges, sleep disorders are also very common for these children (Chevignard & Lind, 2014). Communication deficits and severe impairments in socialization and daily life skills are also present for children who have experienced an abusive head trauma (Chevignard & Lind, 2014). Behavioral disorder “frequency may increase with age, as the consequences of frontal lobe injury may be underestimated unless follow-up is extended into adolescence and early adulthood” (Chevignard & Lind, 2014, p. 554). These delayed deficits require long-term follow-up, which would lead one to believe that this is a normal practice, however, these types of studies are very scarce (Chevignard & Lind, 2014; Lind et al., 2016).

**Educational impact.** Due to the many deficits that children who have experienced an abusive head trauma tend to incur, these children have high rates of special education needs (41%) (Chevignard & Lind, 2014; Lind et al., 2016). In 1996, the United States Congress passed the Traumatic Brain Injury Act, to (a) develop a uniform reporting system to be used by states and (b) to research and report on the incidence and prevalence of the disability to Congress (Lajiness-O’Neill & Erdodi, 2011). The law was later reauthorized as part of the Children’s Health Care Act of 2000, which prompted the dissemination of information regarding Traumatic Brain Injury (TBI) and related disabilities to state agencies (Lajiness-O’Neill & Erdodi, 2011). Initially, TBI was not designated as a specific category under the Education of All Handicapped Children Act (1975), however, children who experienced a TBI received services under Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (Lajiness-O’Neill & Erdodi, 2011). In 1990, Congress passed the Individuals with Disabilities Education Act (IDEA), which amended and replaced the Education of All Handicapped Children Act

(1975). Additionally, Congress identified Traumatic Brain Injury as an eligibility category under IDEA in 1991, defining it as:

An acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. Traumatic brain injury applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. Traumatic brain injury does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma. [Sec. 300.8 (c) (12)]

The designation of TBI as a specific category under IDEA (2004) has increased the eligibility of children affected by an abusive head trauma

for a range of services including an Individualized Education Program (IEP), academic and behavioral supports, as well as occupational, physical, and speech therapies. The reauthorization of IDEA mandated that beginning at age 16, all students who have IEPs must receive services designed to help them successfully transition from high school to adulthood. (Todis, Glang, Bullis, Ettel, & Hood, 2011, pp. 138-139)

With the reauthorization of IDEA (2004) mandating transition services for students receiving special education, students have access to school-to-work opportunities following high school, as well as post-secondary education options (U.S. Department of Education, 2010). In addition to adherence to the federal mandates of IDEA (2004), states may pass additional legislation to “delineate state-specific requirements of the IDEA” (South Carolina Code§ 43-243).

Due to the young age at which children most often experience an abusive head trauma, “impairments (or additional impairments) may only become obvious some years later, with severe consequences on everyday life independence and academic achievements” (Chevignard & Lind, 2014, p. 550). When children who have suffered an abusive head trauma enter school, developmental delays and impairments begin to be identified as “these children fall further behind [their nondisabled peers] over time on many neurocognitive domains” (Vu et al., 2011, p. 264). Additionally:

Children with moderate to severe outcomes have complex disabilities with varying combinations of motor, language, cognitive, and behavioral abnormalities, which all compound significant learning difficulties and require the support of a multidisciplinary team and high levels of care and needs for activities of daily living. (Chevignard & Lind, 2014, p. 554)

For a student who has suffered an abusive head trauma to receive special education services under the TBI category, the following criteria must be met: (a) there is evidence that the child had a traumatic brain injury; (b) it must be demonstrated that the child’s disability "adversely affects their educational performance" and "needs special education and related services" (IDEA, 2004, P.L. 109-446). Once a child qualifies for special education services under the TBI category, a comprehensive assessment of the child’s cognitive, behavioral, academic and social-emotional strengths and weaknesses is essential to determining an appropriate educational program for the child (Lajiness-O’Neill & Erdodi, 2011). A multi-disciplinary team, including both special education and general education teachers, administrators, and other professionals, such as a school psychologist, will meet with the student and the parents or guardians in order to make recommendations for strategies and interventions



to be included in an IEP. Subsequently, “the IEP is reviewed at a minimum of once a year, and adjustments can be made at that time or any time throughout the year if a concern is raised by either the school or the family” (Cheshire, Buckley, Leach, Scott & Scott, 2015, p. 209).

**Direct costs.** Aside from the most pressing human costs involved in a diagnosis of abusive head trauma are the actual monetary costs incurred over the lifetime of the survivor. These costs are exorbitant amounts that are significantly impacting the United States healthcare system (Chevignard & Lind, 2014; Peterson et al., 2014; Stoll & Anderson, 2013). In one study, the four-year total medical costs following diagnosis of abusive head trauma was estimated at \$47,952 per patient and differed for commercially insured by a decrease of approximately \$10,000 (\$38,231) and for Medicaid subscribers by an increase of approximately \$10,000 (\$56,691) (Peterson et al., 2014). Other studies estimate total lifetime costs of patients diagnosed as suffering an abusive head trauma at more than \$124 billion in the United States, with the average costs of surviving patients estimated at \$210,012 annually and at \$1.3 million per fatality (Chevignard & Lind, 2014; Peterson et al., 2014; Stoll & Anderson, 2013). These estimates are not inclusive of other costs incurred by families, such as investments in adequate care throughout a survivor’s lifetime or assistive technologies essential for increased quality of life (Chevignard & Lind, 2014; Peterson et al., 2014; Stoll & Anderson, 2013).

**Lifetime costs.** While there are no studies that focus specifically on life care costs for survivors of an abusive head trauma, some studies provide life care costs for survivors of the larger category of traumatic brain injuries. These costs are discussed here to provide a fuller picture of life care costs that may be associated with surviving an abusive head trauma. One study estimates life care costs for a survivor of a traumatic brain injury to range from \$1.5 million to \$3 million for the duration of a lifetime depending on rehabilitation services utilized

and the effect of these services (Griesbach, Kreber, Harrington & Ashley, 2015). Another study indicates that home assistance provided by a certified nursing attendant would cost \$16.50-19.50 per hour daily and \$180-250 per day for live-in care, while placement in a residential care facility would cost approximately \$450-800 per day for a lifetime (Zasler, Ameis & Riddick-Grisham, 2013). A third study estimates annual life care costs without therapeutic rehabilitation to be \$222,600, while annual life care costs with supervised home placement would be \$49, 688 and annual life care costs with placement in a residential care facility to be \$84,082 (Humphreys, Wood, Phillips & Macey (2013). In addition to these clearly exorbitant life care costs are the costs associated with assistive technologies (AT), which are vital to independence and functioning for someone who has experienced a head trauma (Chu et al., 2014; Oliver, et al., 2015).

*Assistive technologies.* While no studies were found that examined the necessity and costs of assistive technologies (ATs) or cognitive support technologies (CSTs) for survivors of an abusive head trauma, studies revealed the necessity of ATs and CSTs for improving the quality of life for individuals who have experienced a traumatic brain injury (TBI), whether inflicted or acquired. These studies indicate feelings of social isolation and low self-confidence, as well as diminished quality of life for individuals who have experienced a TBI (Chu et al., 2014; Wang, Ding, Teodorski, Mahajan & Cooper, 2016). Since TBIs often result in cognitive deficits for those who are afflicted, many report the most difficulty with organizational tasks and tasks that involve multiple steps (Chu et al., 2014; Wang et al., 2016), which is why ATs and CSTs are so essential to improving and maintaining a positive quality of life for these individuals. Some care teams have begun to utilize in-home gaming systems, such as Microsoft Kinect for XBox, along with software programs such as Virtual Rehab, Teki, Toyra, SeeMe,

Reflexion Health, and Kinelabs to monitor physical progress of patients who have suffered a TBI (Oliver et al., 2015); while cellphones, specifically smartphones, are the most commonly reported ATs utilized to cope with organizational tasks, such as keeping track of appointments or events (Chu et al., 2014; Wang et al., 2016). Although assistive technologies may be utilized to improve the quality of life for those who have experienced a TBI, barriers exist in regards to “reliability, usability, accessibility, and cost” (Chu et al., 2014, p. 283). In addition to “combined impairments (e.g., poor vision, fine motor impairment, etc.),” which affect one’s ability to use technology, ATs and CSTs are often expensive and “individuals with disabilities, including TBI, are far more likely to experience financial hardship, which makes purchasing and using new devices burdensome” (Chu et al., 2014, p. 284). Obviously, one would postulate that it is a worthy endeavor to spend money, time and other resources on the front end in the form of prevention and intervention programs to avoid or deter the risks of abusive head trauma occurring rather than incurring the unconscionable costs of living with a trauma that could and should be avoided.

### **Prevention and Intervention Programs and Strategies**

Prevention and intervention programs targeting abusive head trauma are created with the premise that through education about the risk factors involved, caregivers will understand that inconsolable crying is normal for small infants and that they will also gain some effective coping mechanisms when frustration levels rise. Several prevention programs and strategies are available for use, which have all been confirmed to be effective in increasing the knowledge level of caregivers regarding normal crying patterns and the dangers of shaking an infant (Barr et al., 2009; Bechtel et al., 2011; Stewart et al., 2011; Stoll & Anderson, 2013). The most significant factor, common to each of these programs, is the multi-modal approach to delivery of

the prevention information, which has been found to be most effective in increasing knowledge of normal crying patterns, as well as increasing awareness of abusive head trauma rather than simply including an informational pamphlet into the general hospital discharge papers (Barr, 2012; Shanahan, Nocera, Zolotor, Sellers & Runyan, 2011; Stewart et al., 2011).

**The period of PURPLE crying.** One widely used prevention program, known as *The Period of PURPLE Crying*, developed by the National Center on Shaken Baby Syndrome informs parents of the characteristics of normal crying patterns and why incessant crying leads to frustration (Barr et al., 2009; Stewart et al., 2011). The acronym PURPLE represents each of the properties of normal infant crying patterns:

P for peak pattern, in which crying increases, peaks during the 2nd month and then declines; U for unexpected timing of prolonged crying bouts; R for resistance to soothing; P for pain-like look on the child's face; L for long crying bouts; and E for late afternoon and evening clustering. (Barr et al., 2009, p. 728)

In addition to informing caregivers of normal crying patterns, *The Period of PURPLE Crying* program also suggests methods of soothing, while stressing that soothing may not always be effective and provides three guidelines for infant care (Barr et al., 2009; Stewart et al., 2011). These guidelines include: (a) the use of typical soothing responses, such as carrying, comforting, walking and talking with the infant, (b) putting the infant down in a safe place, walking away and returning to check on the baby after calming down, and (c) never shake a baby (Barr et al., 2009). The *PURPLE Crying* materials include an 11-page booklet and a 12-minute DVD (*Crying, Soothing and Coping: Doing What Comes Naturally*), both of which are available in eight different languages (Barr, 2012; Stewart et al., 2011).

**Take 5 safety plan for crying.** Another effective AHT prevention program, the *Take 5 Safety Plan for Crying* was developed by researchers at Yale-New Haven Children's Hospital to be included into the routine guidance offered by pediatric residents to new parents prior to hospital discharge (Bechtel et al., 2011). The following script is delivered to new parents in English or Spanish, dependent on their primary language, in regards to what to do if a crying becomes frustrating:

The caregiver should put the infant down on his/her back in a safe place, such as the crib or bassinet, or any fixed, firm surface from which the infant would not fall. The caregiver should then walk out of the room. The caregiver is encouraged to do something to relax or calm down, such as meditating, deep breathing, reading, listening to music or doing house chores. The caregiver is encouraged to call a friend, family member, or the infant's doctor for help in dealing with the infant's crying, or to call someone to come to the house to watch the infant if the caregiver wanted to leave the house in order to calm down. The caregiver is advised not to return to the infant's room until he or she is calm enough to safely care for the infant. Crying can be a normal part of an infant's development and does not necessarily indicate that there is something wrong with the infant or the caregiver's ability to soothe the infant. Crying does not hurt infants, but getting frustrated with crying can lead one to shake an infant. The caregiver is reminded never to shake a baby and to remind other caretakers of the baby to never shake a baby. (Bechtel et al., 2011, p. 482)

In addition to having this information relayed to them by a pediatric resident prior to leaving the hospital, new parents are provided with a refrigerator magnet with the *Take 5 Safety Plan for*

*Crying* in their primary language to remind them of the importance of taking a break when crying becomes frustrating once they are at home (Bechtel et al., 2011).

**Additional prevention strategies.** In addition to most prevention programs including a multi-modal delivery including pamphlets, video or audio resources, books, or even home health visits (Stewart et al., 2011), some programs incorporate a commitment signature from the parents or primary caregivers, signifying commitment to recognize the risk of potential harm and to take the necessary steps to avoid causing an abusive head trauma (Altman et al., 2011; Stoll & Anderson, 2013). In order to provide a more holistic approach to help caregivers understand the important connection between personal responsibility, morality and forming connections with others, a spiritual component has been added to one prevention strategy (Stoll & Anderson, 2013). Clearly, multi-modal prevention strategies work best, but of more urgency is grasping how and when to implement these strategies. One quantitative study on prevention and intervention strategies found three themes in effective prevention: caregiver education, early detection and implementation of prevention strategies, and community involvement (Stoll & Anderson, 2013).

**Caregiver education.** While factors have been determined that seem to point to increased risk of an abusive head trauma occurring within specific demographics, the reality is that shaking or abuse can occur at the hands of any caregiver whose tolerance for inconsolable crying has been exceeded if the caregiver is not informed of the dangers of such actions (Barr, 2012). It is essential that prevention and intervention strategies be distributed to all parents rather than just those with identified risk factors. In a quantitative study involving 112 pediatric caregivers (Bechtel et al., 2011), new parents received a brief educational intervention, provided by a pediatric resident prior to hospital discharge, to influence beliefs regarding infant crying and

were provided coping mechanisms to successfully address incessant crying. As a result, caregivers reported increased knowledge regarding crying and coping mechanisms weeks after the intervention (Bechtel et al., 2011). A similar quantitative study was carried out in France (Simonnet et al., 2014) where new parents were briefed on normal crying and provided information regarding abusive head trauma. Following the study, parents reported increased knowledge of normal infant crying and healthy ways to cope (Simonnet et al., 2014). Additional quantitative studies have confirmed that prevention methods relayed as part of postpartum education programs have significantly increased caregiver knowledge regarding normal crying and the use of effective strategies to cope with inconsolable crying in infants (Altman et al., 2011; Fujiwara et al., 2012; Keenan & Leventhal, 2010).

***Early detection and implementation of prevention strategies.*** Several cross-cultural studies have confirmed what is referred to as the “normal crying curve,” in which daily overall crying increases weekly, peaks in the second month and returns to lower levels by month four or five (Barr, 2012, 17296). For this reason, prevention and intervention strategies must be introduced to parents and caregivers during the perinatal period, targeting those early bouts of incessant crying prior to the fourth or fifth month of infancy. Pediatric nurses and other medical personnel serve as key contacts in early detection and implementation of prevention strategies, therefore it is essential that they are properly educated to allow for successful detection of potential warning signs and successful delivery of prevention strategies (Stoll & Anderson, 2013). In one study, registered nurses reported a 47% increase in knowledge regarding crying patterns and abusive head trauma following a training program involving information about normal infant crying, soothing strategies to help calm crying infants, the epidemiology of abusive head trauma, risk factors that lead to AHT, and outcomes of AHT (Stewart et al., 2011).

Another study implemented a prevention strategy by having new parents view an informational DVD on normal crying, soothing and coping techniques prior to hospital discharge with a trained registered nurse on hand to answer any follow up questions (Stewart et al., 2011). The authors of the study reported that “nearly all (93%) parents rated the program as useful, citing ‘what to do when crying becomes frustrating’ as the most important message, which suggests that early implementation is essential to prevention of abuse (Stewart et al., 2011, p. 1804). Another study reported that 95% of caregivers who participated in a prevention program prior to hospital discharge indicated that their knowledge of normal crying and abusive head trauma was gained directly from hospital staff (Bechtel et al., 2011).

***Community involvement.*** The adage *it takes a village to raise a child* is especially true in the current era, where shifting family and societal expectations and values increase the likelihood that infants and children will be taken care of by people outside of their immediate family, increasing the need for community involvement in the prevention of abusive head trauma. Knowledgeable community members may promote early detection of at risk behaviors, increasing early intervention efforts to prevent abuse. One study implemented a media campaign based on the *Period of PURPLE Crying* (Barr et al., 2009) to inform the community of normal crying patterns and attempting to normalize crying as a part of healthy infant development (Stewart et al., 2011). The suggestions offered by the *Take 5 Safety Plan for Crying* (Bechtel et al., 2011) allows the caregiver to build community and avoid acting out of frustration, which may result in violence towards the child (Stoll & Anderson, 2013). Community awareness may create a sense of advocacy for federal initiatives requiring all caregivers who work with infants and small children to be trained to understand normal patterns of crying, to recognize the danger



of shaking an infant, as well as signs of abuse so that early intervention or detection of suspected cases is possible (Stoll & Anderson, 2013).

### **Qualitative Literature on Adolescents with Traumatic Brain Injury**

Upon conducting a review of the literature relating to abusive head trauma, I attempted to locate qualitative studies on adolescents who have suffered a traumatic brain injury, since abusive head trauma is a type of TBI, in order to gain insight into the adolescent survivor experience. As was the case with literature regarding abusive head trauma, I was unable to find any qualitative studies specifically regarding the role of resilience in the experiences of adolescent survivors of a traumatic brain injury. Of the qualitative studies I located regarding TBI, very few focused on the experience of adolescent survivors and even fewer included the perspective of adolescent survivors.

While a few qualitative studies focused on the role of supporting parents whose child experienced a traumatic brain injury (Keenan & Joseph, 2010; Kirk, Fallon, Fraser, Robinson, & Vassallo, 2015; Lefebvre & Levert, 2012), others focused on the challenges of an adult sibling following a TBI suffered by a younger brother or sister (Degeneffe & Bursnall, 2015; Degeneffe & Lee, 2010; Degeneffe & Olney, 2010). While these studies provide insight into life adjustments required by the family, these studies included only the voices of parents, professionals, and other adults, failing to include those of the adolescent survivors of a TBI.

Three qualitative studies focus on the experiences and include the perspectives of adolescent survivors of a traumatic brain injury (Gauvin-Lepage & Lefebvre, 2010; Iadevaia, Roiger, & Zwart, 2015; Mealings & Douglas, 2010). Adolescent survivors in two of the studies (Gauvin-Lepage & Lefebvre, 2010; Mealings & Douglas, 2010) incurred traumatic brain injuries due to accidents involving motor vehicles, skiing, and bicycling and their injuries ranged from

moderate to severe, indicating a “length of post-traumatic amnesia greater than 1 week” (Mealings & Douglas, 2010, p. 4). Adolescent survivors who participated in the third study, incurred a moderate TBI following a sports-related concussion (Iadevaia et al., 2015).

Four inter-related themes emerged regarding adolescent experiences with TBIs across all three studies: “(a) significant effects of symptoms, (b) feelings of frustration, (c) influence on school activities and attendance, and (d) nature of interpersonal and team relationships” (Iadevaia et al., 2015, p. 1182). In each of the three studies, the participants and their families reported physical symptoms following the occurrence of a TBI, which included: nausea, fatigue, headaches, dizziness, sensitivity to light and sound, vision impairment, and difficulty in the areas of concentration, mobility, communication and learning (Gauvin-Lepage & Lefebvre, 2010; Iadevaia et al., 2015; Mealings & Douglas, 2010). All three studies emphasized that the physical symptoms following the occurrence of a TBI had a significant effect on adolescents’ level of frustration, school attendance and participation in school activities and interpersonal relationships (Gauvin-Lepage & Lefebvre, 2010; Iadevaia et al., 2015; Mealings & Douglas, 2010). Though the adolescent participants in all three studies were determined to return to school following their injuries, all expressed frustration regarding the amount of time necessary to complete cognitive tasks and concern over feeling as if they were being left behind academically due to absence from school that resulted from the intensity of physical symptoms, specifically headaches and fatigue (Gauvin-Lepage & Lefebvre, 2010; Iadevaia et al., 2015; Mealings & Douglas, 2010). While these adolescent survivors reported that in some cases they had experienced distance or loss of friendships due to their injuries, most indicated that their teammates and friends had been generally supportive (Gauvin-Lepage & Lefebvre, 2010; Iadevaia et al., 2015; Mealings & Douglas, 2010). Some adolescent participants and their

families indicated that their interactions within the family were sometimes more confrontational than those prior to their injuries, and often occurred as a result of frustration on the part of the adolescent participant (Iadevaia et al., 2015). However, most of the adolescent survivors and their family members discussed that their family bonds had strengthened as a result of their injuries (Gauvin-Lepage & Lefebvre, 2010; Iadevaia et al., 2015; Mealings & Douglas, 2010).

These qualitative findings are important, but only provide a glimpse into one aspect (the school environment) of the experiences of adolescent survivors of a traumatic brain injury. All of these survivors were in some stage of recovery during the studies in which they participated and all were expected to make a full recovery over time, unlike children who have experienced an abusive head trauma, from which there is significantly less likelihood of a full recovery. Also, of importance, is the fact that all of the participants in the aforementioned studies incurred their injuries as adolescents, rather than as infants, such as those suffered by children who experience an abusive head trauma. Though some of the findings may be similar for an adolescent survivor of an abusive head trauma regarding the school environment, life does not only exist within the realm of the school environment. It is essential to study the life history of the challenges faced and coping mechanisms utilized by an adolescent survivor of an abusive head trauma in order to gain a full understanding of lived experience.

### **Summary**

Abusive head trauma is “an extremely serious form of inflicted brain injury,” as a result of “violent shaking, with or without impact, of an infant by an adult” (Chevignard & Lind, 2014, p. 548). Abusive head trauma is a serious and growing healthcare concern in the United States, with an estimated annual incidence rate of 14-32 cases per 100,000 infants younger than 12 months of age (Bechtel et al., 2011; Parrish et al., 2013; Peterson et al., 2014; Stoll & Anderson,

2013; Xiang et al., 2013). The current literature provides a statistical background regarding the prevalence, outcomes, deficits, risk factors, signs and symptoms, direct costs, and prevention strategies involved with abusive head trauma. As evidenced by the abundance of quantitative studies on various aspects of abusive head trauma, and a dearth in qualitative studies regarding this phenomenon, there is clearly a gap in the literature. While the diagnoses for children suffering abusive head trauma range in severity from mild to severe, with the worst outcomes expected in the severe category, a small percentage (13%) of survivors have “good outcomes,” indicating an ability to attend regular classes, while requiring remedial resources, however, these children may continue to exhibit behavioral disorders (Lind et al., 2016, p. 361). Explicit evidence in the literature established that long-term follow up on these children is essential to gain a complete understanding of the challenges they face and the supports they need later in adolescence and adulthood (Chevignard & Lind, 2014; Lind et al., 2016). There is currently no research telling the life story of an individual who has experienced and coped with abusive head trauma.

## **CHAPTER THREE: METHODS**

### **Overview**

The purpose of this narrative study is to describe the life history of an adolescent survivor of an abusive head trauma in the Southeastern United States. In this chapter, I outline the research design, as well as the research questions, setting, and introduce the primary and secondary participants in the current study. Procedures are discussed so that reasonable replication could be carried out, including the researcher's role, data collection, data analysis, trustworthiness and ethical considerations.

### **Design**

When considering the research method most appropriate for this study, a qualitative methodology emerged. According to Creswell (2013):

Qualitative researchers use an emerging approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is both inductive and deductive and establishes patterns or themes. The final written report or presentation includes the voices of participants, the reflexivity of the researcher, a complex description and interpretation of the problem, and its contribution to the literature or a call for change. (p. 44)

Qualitative research, unlike quantitative research, allows the researcher to “empower individuals to share their stories” and have their voices heard (Creswell, 2013, p. 48). The current research study places emphasis on empowering an adolescent survivor of abusive head trauma to share her story and to have her voice heard.

Originating from various fields across the humanities disciplines (i.e., literature, history, anthropology, education, etc.), narrative research is “an approach to the study of human lives

conceived as a way of honoring lived experience as a source of important knowledge and understanding” (Clandinin, 2013, p. 17). Narrative research is more than a biography or storytelling, as “the focus of narrative inquiry is not only valorizing individuals’ experience but is also an exploration of the social, cultural, familial, linguistic, and institutional narratives within which individuals’ experiences were, and are constituted, shaped, expressed, and enacted” (Clandinin, 2013, p. 18). Riessman (1993) stated:

A fully formed [narrative] includes six common elements: an abstract (summary of the substance of the narrative), orientation (time, place, situation, participants), complicating action (sequence of events), evaluation (significance and meaning of the action, attitude of the narrator), resolution (what finally happened) and coda (returns the perspective to the present). (p. 18)

More specifically, within the narrative inquiry methodology is a design known as life history. The purpose of a life history is “to inquire into lived experiences and to represent that experience in a narrative form that provides rich detail and context about the life in question” (Gough, 2008, p. 484). According to Clandinin (2013), narrative inquirers:

understand that people *live* out stories and *tell* stories of their living. Narrative inquirers come alongside participants. . . and begin to engage in narrative inquiry into our lived and told stories. We call this process of coming alongside participants and then inquiring into the lived and told stories *retelling* stories. Because we see that we are changed as we retell lived and told stories, we may begin to *relive* our stories. (p. 34)

A life history narrative was the most appropriate qualitative design for this research study as I sought to “provide accounts and analyses of how” an adolescent survivor of an abusive head trauma that occurred when she was five months old “make[s] sense of [her] lived experience in

the construction of both individual and social identity” (Gough, 2008, p. 484). Allowing Trudy to share her story in her own voice and through the collection of stories that emerged from Trudy and secondary participants provided a thick, rich description of her experience of living with and coping with an abusive head trauma.

### **Research Questions**

The current study is framed by the following research questions:

**Central Question:** What are the lived experiences of an adolescent survivor of an abusive head trauma in the Southeastern United States?

**Sub-Question 1:** What challenges does an adolescent survivor of an abusive head trauma face?

**Sub-Question 2:** What resilience mechanisms does an adolescent survivor employ to cope with living with an abusive head trauma?

**Sub-Question 3:** What advice would an adolescent survivor give to someone who has experienced an abusive head trauma?

### **Setting**

This study was conducted in the Upstate of South Carolina, in and around the city where Trudy, the primary participant resides. Located in a large metropolitan county where Trudy was born and has grown up, there is one major research hospital nearby, as well as a children’s hospital, where Trudy received most of her early medical care. This area is also home to several institutions of higher education. Interviews were conducted in various locations with consideration given to convenience, familiarity, privacy and significance for Trudy and secondary participants. Travel outside of the primary setting was necessary to obtain data not available in the primary setting. Interviews were also conducted via telephone and Skype.

Observations were conducted in Trudy's home and other social settings that I was allowed to participate in, such as attending church, a family camping trip (Appendix D), and a family meal.

### **Participants**

In purposeful sampling, "the inquirer selects individuals and sites for study because they can purposefully inform an understanding of the research problem and central phenomenon of the study" (Creswell, 2013, p. 156). Trudy, the primary participant in this study was purposefully selected based on her personal experience as an adolescent survivor of an abusive head trauma. Secondary participants in this study were purposefully selected based on their ability to inform an understanding of Trudy's lived experiences as an adolescent survivor of an abusive head trauma.

In narrative research, it is acceptable to have a small sample, as "narrative inquiry is situated in relationships and in community, and it attends to notions of expertise and knowing in relational and participatory ways" (Clandinin, 2013, p. 13). A small sample size allowed me to spend an extended amount of time building and nurturing the relationships necessary to gain a thick, rich description of the stories that must be told to reveal a life history (Clandinin, 2013; Clandinin & Connelly, 2000). The primary participant is a 19-year-old, Caucasian, female, referred to by the pseudonym Trudy, who is a survivor of an abusive head trauma, which occurred when she was five months old. Though the primary participant is a single individual, secondary participants were included in order to develop a holistic understanding of Trudy's life history, especially the earlier years of her life, which she could not recall.

Secondary participants in this study included Trudy's family members, a family friend, a special education classroom teacher, and a church youth leader. In keeping with Bronfenbrenner's (1979) ecology of human development and Clandinin's (2013) emphasis on



exploring social, cultural, familial, linguistic and institutional narratives, an individual life cannot be studied in isolation, but must be examined in the contexts of the many systems and environments that influence the individual's life, such as Trudy's home, her school, and the church that she and her family attend. Gaining insight from secondary participants, including Trudy's mother, step-father, sister, family friends and teachers was essential for triangulation in this study and helped add to the thick, rich description of her life history, which is required of qualitative research (Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007).

### **Procedures**

All research, whether quantitative or qualitative, follows some pattern reflective of the scientific method. However, qualitative research tends to include more flexibility and be more emergent in design than quantitative research. Creswell (2013) stated, "all researchers start with an issue or problem, examine the literature in some way related to the problem, pose questions, gather data and then analyze them, and write up their reports" (p. 50). In narrative research, "inquiry is fluid, not a set of procedures or linear steps to be followed but a relational inquiry methodology that is open to where the stories of participants' experience take the researcher" (Clandinin, 2013, p. 33). General procedures for conducting narrative research include: (a) determining whether the narrative approach is appropriate for the research problem, (b) collecting data in the form of stories or field texts, (c) considering the shape that the collection of data and their recording will take, (d) collecting information regarding the context of the stories, (e) analyzing the participants' stories and (f) collaborating with participants to validate the stories and narrative as a whole (Clandinin, 2013; Clandinin & Connelly, 2000; Creswell, 2013). The current study is a narrative life history of an adolescent survivor of an abusive head trauma that occurred when she was five months old.

Prior to beginning data collection, approval was gained from the Institutional Review Board (IRB). As Trudy clearly expressed a desire to tell her story, I gained preliminary consent from Trudy and her mother. Trudy's mother contacted her current and former teachers, as well as Trudy's church youth leader to discuss their potential involvement in the study. During these conversations, Trudy's mother gave her consent for these potential participants to discuss their insight into Trudy's challenges and coping mechanisms as well as gaining preliminary consent to participate, if contacted by me. Following IRB approval (Appendix A) and after introductions to secondary participants by Trudy and her mother were made to ensure permission had been given to discuss Trudy's experiences with me, informed consent was obtained for all adult participants (Appendix B), as well as informed assent for Trudy's 16-year-old sister (Appendix C) prior to any data collection. Since Trudy, the primary participant, is of legal age (19), even though her mother has been granted legal guardianship of her based on the cognitive deficits Trudy has developed due to her injury, gaining informed consent was appropriate for Trudy to participate.

The following sections examine the role of the researcher and provide specific procedures for data collection and analysis. This chapter closes with a discussion of trustworthiness and ethical considerations.

### **The Researcher's Role**

In qualitative research, such as this current study, the researcher serves as the human instrument to collect and analyze the data (Creswell, 2013). The qualitative researcher must physically collect data through an extensive process including interviews and observations and pore over copious documents and artifacts, while engaging in structuring and restructuring a narrative all throughout the analysis process (Clandinin & Connelly, 2000; Riessman, 1993;

Riessman, 2008). For this study, it was essential that I took on the role of a participant observer as I “stud[ied] [Trudy’s] experience in the world, an experience that is storied both in the living and telling and that [was] studied by listening, observing, living alongside [her], and writing, and interpreting texts” (Clandinin, 2013, pp. 42-43).

Since a researcher’s paradigm and assumptions naturally influence analysis, I will take a moment to discuss my own paradigms and assumptions here. As a secondary social studies teacher in a public-school setting for the past 14 years, I have been held accountable for staying abreast of the latest research in my field and putting that research into practice. As a student, I have obtained a B.A. in History, M.Ed. in Education, and an Ed.S. in Educational Leadership and I am currently pursuing an Ed.D. in Curriculum and Instruction. I have conducted many small-scale research projects throughout my educational career and I understood the commitment that a study such as this required.

As a public-school teacher, I am in a state of constant analysis, serving as a human instrument, to interpret what is working and not working for students in my classroom. Throughout my career, I have served on numerous committees to aggregate data regarding student achievement, as well as how students experience schooling. I have designed, utilized, and analyzed open-ended questionnaires and surveys to obtain feedback on students’ experiences in my classroom, as well as in school and district-wide curriculum programs. This data collection method required that I group responses into themes for the data to be useful to me and others to inform decisions regarding successes or changes that should be made to increase student achievement. I was grateful to be included in a group of my peers called upon to analyze open-ended feedback from students, teachers, parents, administrators and other community leaders regarding the social studies curriculum in my state and to use that analysis to inform

changes that needed to take place in the state standards as this experience prepared me for the research that I have conducted as a doctoral candidate engaged in a qualitative study.

### **Data Collection**

Creswell (2013) discussed data collection common to all qualitative approaches as a “circle of interrelated activities” and further explained that these activities include “gaining permissions, conducting good qualitative sampling strategy, developing means for recording information both digitally and on paper, storing data, and anticipating ethical issues that may arise” (p. 145). Narrative research places emphasis on the stories of individuals, therefore it was imperative to collect various types of data to gain a thick, rich description and to add to the validity of the study through the triangulation of data (Schwandt, 2015). In triangulation, “the fieldworker makes inferences from data, claiming that a particular set of data supports a particular definition, theme, assertion, hypothesis, or claim. Triangulation is a means of checking the integrity of those references” (Schwandt, 2015, p. 307). As an integral part of narrative research, “triangulation is both possible and necessary because research is a process of discovery in which the genuine meaning residing within an action or event can be best uncovered by viewing it from different vantage points” (Schwandt, 2015, p. 308). Triangulation can be conducted in multiple ways. For example, Czarniawska (2004) proposed that data be collected for stories by: “recording of spontaneous incidents of storytelling through prolonged field research, . . . eliciting stories through interviews,” and requesting that stories be shared through digital media available on the Internet (pp. 42-44). Another method of triangulation of data is through the collection of multiple and varied field texts (Clandinin, 2013; Clandinin & Connelly, 2000; Riessman, 1993; Riessman, 2008). According to Clandinin (2013):

Field texts are the records, including, for example, field notes, transcripts of conversations, and artifacts, such as photographs and writings by participants and researchers. Artifacts often included in the field texts are artwork, photographs (both memory box and intentionally taken recent photographs), other memory box items, documents, plans, policies, annals, and chronologies. Field texts allow us ways to see how others make meaning from experience and may also point us to possibilities of diverse final research texts – that is the diverse ways we might represent the retold stories.” (p. 46)

After IRB approval was secured and informed consent for adult participants and informed assent for Trudy’s younger sibling was obtained, data collection was conducted through interviews with Trudy and secondary participants; field notes were gathered from observations and documents and artifacts were obtained, as well as a six-week audiovisual journal completed by Trudy.

### **Interviews**

Interviewing is frequently used in qualitative research as an appropriate and primary method of gaining a human perspective on lived phenomena (Clandinin, 2013; Clandinin & Connelly, 2000; Creswell, 2013; Riessman, 1993; Riessman, 2008). According to Clandinin (2013):

The most frequently used starting point is telling stories, and the methods most commonly used are conversations, or interviews as conversations. Conversations are not guided by predetermined questions, or with intentions of being therapeutic, resolving issues, or providing answers to questions. (p. 46)

Riessman (1993) stated that “interviews are conversations in which both participants-teller and

listener/questioner-develop meaning together, a stance requiring interview practices that give considerable freedom to both” (p. 55). Therefore, interview questions were broad, open-ended and grounded in the literature. After arriving at the interview site, which included Trudy’s home and other locations chosen by her or secondary participants, I obtained a consent/assent form for each interviewee before beginning the interview. Semi-structured interviews were conducted with Trudy, an adolescent survivor of an abusive head trauma, as well as with secondary participants, including her mother, step-father, younger teen-aged sister, adopted father, grandfather, step-grandmother, a family friend, a church youth leader and a current special education teacher (Creswell, 2013).

Interview protocols created for each participant were utilized during each semi-structured interview to maintain the focus of the study. Two expert reviews of the initial interview protocols were conducted to ensure content and face validity (Creswell, 2013). Both reviewers hold doctoral degrees and both have extensive experience in psychology. One reviewer is employed as an adjunct professor of education at a local four-year university, while also serving as a full-time teacher for at-risk youth and host of an annual summer camp program for children with disabilities. The second reviewer is a licensed clinical psychologist and associate professor of psychology at a large, private, non-profit Christian university. These experts reviewed the initial interview protocols, checking for alignment with the research questions, as well as for sensitivity towards Trudy and the secondary participants. Both reviews indicated that the initial interview protocols for all secondary participants were appropriate, while both made suggestions for improving the interview questions for Trudy. One reviewer suggested that I focus on Trudy’s abilities and positive characteristics prior to moving on to more challenging questions. The second reviewer suggested that I conduct the secondary participants’ interviews prior to

interviewing Trudy, as secondary participants may reveal aspects of Trudy's story that I may want to discuss with Trudy when I interview her. He also suggested that I delve deeper into how Trudy views herself and her future. I edited my initial interview protocols for Trudy and her mother to incorporate this feedback and I interviewed all secondary participants before interviewing Trudy.

Carr (1986) stated that "to live this story is to tell it, to ourselves and possibly to others; and in this case to retell it again and again, revising as we go along" (pp. 95-96). Therefore, follow up protocols for a second semi-structured interview with Trudy's mother were created after the analysis of initial data, to follow a research spiral to "compose research texts that the researcher and participants [saw] as authentic and compelling" (Clandinin, 2013, p. 47). Each interview was audio recorded using two digital voice activated recorders, and transcribed following the interviews, as recording and transcription are "absolutely essential to narrative analysis" (Riessman, 1993, p. 56).

The initial interview protocols are included below beginning with Trudy's mother, as she provided the most insight into Trudy's lifelong challenges and the coping mechanisms Trudy has employed since childhood as Trudy could not recall challenges that she faced as a young child. This is followed by the initial interview protocols for Trudy's step-father and her sister, as they provided even more insight into the challenges that Trudy faces and the coping mechanisms that Trudy employs daily. Next, I have included the initial interview protocol that was utilized when speaking with Trudy's teacher, followed by the one that was utilized when interviewing Trudy's church youth leader, other family members, and a family friend, to provide a thick, rich description of the challenges Trudy faces and the coping mechanisms she employs in academic and social settings. Finally, I have included the initial protocol that was utilized when

interviewing Trudy, as my initial interviews concluded with Trudy telling her own story regarding the challenges she faces and the coping mechanisms she employs as a survivor of an abusive head trauma.

#### Initial Interview Protocol for Trudy's Mother

1. Please tell me about what happened to Trudy.
2. How much does Trudy know about what happened to her?
3. What was Trudy like as a child?
4. When did Trudy begin talking? Walking? Feeding herself? Reading? Taking care of her own personal hygiene? Dressing herself? Cleaning up after herself? As far as when Trudy began doing these things, what, if any, differences occurred between her and her sister?
5. What are some physical challenges that you may have noticed for Trudy? How does Trudy cope with physical challenges?
6. Tell me about Trudy's experience with seizures.
7. Describe any hearing or visual impairments that Trudy has experienced throughout her life.
8. Describe any academic challenges that Trudy experiences. How have these challenges been addressed at school? How does Trudy cope with these challenges?
9. What types of behaviors has Trudy displayed that her sister either did not display at all or displayed at a younger age than Trudy? (i.e., temper tantrums, acting out)
10. How does Trudy deal with anger or frustration? Sadness?
11. Tell me about Trudy's ability to remember things and to stay organized.
12. How does Trudy respond to challenges? How have Trudy's responses to things she finds



difficult changed as she has gotten older?

13. How would you describe Trudy's general disposition and outlook on life? What do you attribute this to?
14. Tell me what you envision for Trudy's future. What types of challenges will Trudy face as an adult? How will she cope with these challenges?
15. What else would you like to share that would help me to get a full picture of the challenges that Trudy faces? Or the successes that she experiences?

#### Initial Interview Protocol for Trudy's Step-father

1. How old was Trudy when you first met her?
2. When did Trudy's mother tell you about what had happened to Trudy? How did that make you feel?
3. What was your initial impression of Trudy?
4. How would you describe Trudy's general disposition and outlook on life? What do you attribute this to?
5. What are some physical challenges that you may have noticed for Trudy? How does Trudy cope with physical challenges?
6. Describe any academic challenges that Trudy experiences. How does Trudy cope with these challenges?
7. What other kinds of challenges have you seen Trudy experience? How does Trudy cope with these challenges?
8. Describe a time when Trudy overcame a challenge that took you by surprise.
9. What kinds of changes have you seen in Trudy over the years?
10. Tell me what you envision for Trudy's future. What types of challenges will Trudy face

as an adult? How will she cope with these challenges?

11. What else would you like to share that would help me to get a full picture of the challenges that Trudy faces? Or the successes that she experiences?

#### Initial Interview Protocol for Trudy's Sister

1. Describe what it has been like to have Trudy as a sister.
2. When did you learn about Trudy's injury? How did that make you feel?
3. When you two were little kids, did you notice any differences between you and your sister? Please explain.
4. What kinds of challenges have you seen Trudy experience as you two have gotten older?
5. How does Trudy handle challenges? What does she do to overcome difficulty?
6. How do you think Trudy will adjust to life without her sister when you leave for college?
7. What do you envision for Trudy's future?
8. What else can you share that would help me to get a full picture of the challenges that Trudy faces? Or the successes that she experiences?

#### Initial Interview Protocol for Trudy's Teacher(s)

1. How long have you known Trudy?
2. Describe the academic challenges that Trudy experiences.
3. What types of special education services does Trudy receive at school?
4. What types of behaviors has Trudy displayed in the classroom?
5. How does Trudy handle challenges or difficult situations in the classroom?
6. Tell me about Trudy's ability to stay organized at school. What challenges does she face with organization? How does she cope with these challenges?
7. What types of vocational skills has Trudy gained as part of school experience? What do

you feel have been challenges she has faced during these experiences? Successes?

8. What opportunities does Trudy have for school or work after she finishes high school?
9. Tell me what you envision for Trudy's future. What challenges will she face as an adult?  
How will she cope with these challenges?
10. What else would you like to share that would help me to get a full picture of the challenges that Trudy faces? Or the successes that she experiences?

#### Initial Interview Protocol for Other Family Members and Friends

1. How do you know Trudy and for how long have you known her?
2. How would you describe Trudy to someone who does not know her?
3. Describe the challenges that you have seen Trudy experience.
4. How does Trudy cope with these challenges?
5. What is Trudy's general disposition and outlook on life? What do you attribute this to?
6. What do you envision for Trudy's future?
7. What else would you like to share that would help me to get a full picture of the challenges that Trudy faces? Or the successes that she experiences?

#### Initial Interview Protocol for Trudy

1. Tell me about yourself. How would you describe yourself to someone who does not know you?
2. What kinds of things do you enjoy doing?
3. Tell me about something that you are great at.
4. Tell me about your family. What kinds of things do you like to do together? Are there things that your family likes to do that you think are hard to do?
5. Tell me about your childhood. What kinds of things did you enjoy doing when you were

- little? What kinds of things did you not enjoy as a child?
6. When did you learn what happened to you (that you had an abusive head trauma)?
  7. How did you feel when your mom told you what happened? How do you feel about it now?
  8. Describe your school day to me. What do you enjoy about school? What do you think is hard about school?
  9. When you have a hard time doing something, how do you deal with things that are hard for you to do? How do you make sure you get help when you need it?
  10. When you think about your future, what does that look like to you?
  11. What do you think might be hard for you to do in your future? How do you feel about that? How will you deal with challenges in your future?
  12. What advice would you give to someone your age who has the same challenges as you?
  13. Would you like to tell me anything else about yourself that would help me to tell your story better?

The purpose of the initial interview protocols was to begin to construct a narrative life history of Trudy's experience as an adolescent survivor of an abusive head trauma. The initial questions in each set of interviews were meant to build background for Trudy's story, as indicated in Question 1 for Trudy and her teacher, Questions 1 and 2 for Trudy's mother, sister, church youth leader and family friends, and Questions 1 through 3 for Trudy's step-father. Most of the questions in all interview protocols address the challenges that Trudy faces as an adolescent survivor of an abusive head trauma, which are related to Research Sub-question 1: What challenges does an adolescent survivor of an abusive head trauma face? As indicated by the literature, these include neurological, cognitive, behavioral, and educational challenges

(Chevignard & Lind, 2014; Lind et al., 2016; Stoll & Anderson, 2013). Specific interview questions addressing these challenges are reflected in Table 2. Experiencing trauma at such a young age and then surviving that trauma requires a significant degree of resilience on the part of the survivor (Aburn, Gott & Hoare, 2015; Fletcher & Sarkar, 2013; Wu et al., 2013). A large portion of the remaining interview questions in all interview protocols are devoted to resilience mechanisms that Trudy uses to cope with challenges, which are related to research sub-question 2: What resilience mechanisms does an adolescent survivor employ to cope with living with an abusive head trauma? Specific interview questions addressing resilience mechanisms are reflected in Table 2. Question 11 in Trudy's interview protocol addresses research sub-question 3: What advice would an adolescent survivor give to someone who has experienced an abusive head trauma? When crafting Trudy's life history, it was of the utmost importance that I not only understood where she has come from and where she is, but where she is going (Clandinin, 2013). Trudy's future aspirations are also considered and specific interview questions addressing this topic are reflected in Table 2. The final question in each interview protocol allowed Trudy and all secondary participants to share any other information regarding challenges that she has faced or successes that she has experienced to gain a full picture of Trudy's life experiences.

Table 2

*Interview Questions Regarding Challenges and Resilience Mechanisms*

	Trudy	Mother	Step-father	Sister	Teacher(s)	Family Friend(s)
<i>Challenges</i>	4-7	4-11	5-7	3-4	2, 4, 6-8	3, 7
<i>Resilience Mechanisms</i>	2-3, 8	4, 7, 9, 12-13	4-9	5	3, 5-7	4-5, 7
<i>Future Aspirations</i>	10-12	14	10	7	9	6

**Observations**

According to Clandinin (2013), “most narrative inquiries begin with telling stories, that is with a researcher engaged in conversations with participants who tell stories of their experiences” (p. 34). However, “a more difficult, time-consuming, intensive, and yet, more profound method is to begin with participants’ living, because in the end, narrative inquiry is about life and living” (Connelly & Clandinin, 2006, p. 478). Observation in qualitative research is an essential tool during which the researcher may “watch physical setting, participants, activities, interactions, conversations and their own behaviors during the observation” (Creswell, 2013, p. 166). Clandinin (2013) stated that narrative inquirers “become part of participants’ lives and they part of ours. Therefore, our lives- and who we are and are becoming, on our and their landscapes- are also under study” (p. 30). I took on the role of participant observer during this study as Clandinin (2013) emphasized the thick, rich description that can be gained through informal observation:

When we situate our inquiries primarily in the living of stories, we go where participants take us; we meet their families and/or friends; we go to the places they take us. In living alongside participants, we enter places that are important to participants. The places and

relationships we become part of when we begin with living alongside participants call forth stories we, and they, tell.” (p. 45)

As Trudy and her family allowed me to become a part of her life, I was fortunate to participate in family events, such as a camping trip, and the celebration of school achievements, as well as daily routines such as a family meal. I gathered field notes during and immediately following informal observations in the form of a research journal. To journal, I used an observation protocol (Appendix D) containing both descriptive and reflective notes regarding the observations, “attending simultaneously backward and forward, inward and outward, with attention to place” (Clandinin, 2013, p. 39). Place is defined as “the specific concrete, physical, and topographical boundaries of place or sequences of places where the inquiry and events take place” (Connelly & Clandinin, 2006, p. 480).

### **Document and Artifacts**

Following the initial interviews, I collected documents provided by Trudy and her family, that helped to provide a thick, rich description of the challenges that Trudy has faced, as well as those that provided insight into the coping mechanisms she has employed in surviving an abusive head trauma. Graciously, provided by the parents, medical records and Individualized Education Programs were examined to understand challenges that Trudy has faced, as well as how she has overcome those challenges. To gain insight into Trudy’s past, present and future, documentation was collected in the form of personal-family-social artifacts from Trudy and family members, as well as photographs of Trudy throughout various life stages. Artwork created by Trudy throughout her school career were also examined for their significance to Trudy and to her family in regard to the challenges she has faced and the ways in which she has coped with those

challenges, but the findings were not significant (Clandinin, 2013; Clandinin and Connelly, 2000; Creswell, 2013).

### **Audiovisual Journal**

Audiovisual materials were collected in the form of a participant video journal recorded during the research process (Creswell, 2013; Yin, 2009). Trudy was asked to use her iPad to record a brief video in which she was asked to respond to the following prompt: What was hard for me this week? What good things happened this week? This allowed Trudy to discuss challenges or triumphs on a weekly basis throughout the data collection period. She was asked to submit the videos to me by email, with her mother's assistance, on Sunday each week and did so for a period of six weeks.

### **Data Analysis**

Gough (2008) stated, "the analysis of the social, historical, political and economic contexts of [life] experiences is what transforms a life story into a life history" (p. 484). In this narrative study of an adolescent survivor of an abusive head trauma, data analysis began with the organization of files for data collection. Continuing analysis involved the tedious task of transcribing interviews from audio-recordings. During each of the interviews, I used two digital audio-recording devices and took notes on a copy of the interview protocol. I wrote down short phrases that stood out, as well as changes in body language or tone as I watched and listened to each participant's response. All interviews were transcribed by me on my personal laptop immediately following the interview with each participant. Riessman (1993) revealed that transcription is an area that requires a notable amount of work on the part of the transcriber, which for this study was me, and suggested that researchers:



begin with a rough transcription, a first draft of the entire interview that gets the words and other striking features of the conversation on paper (e.g., crying, laughing, very long pauses). Then go back and re-transcribe selected portions for detailed analysis. (p. 56)

As I listened back to the audio-recordings and compared them to my notes, I included notes on body language or changes in tone in the transcriptions. These files were saved and stored in a password protected digital folder on my laptop and another copy was saved to my digital cloud, which is also password protected. To engage in member checking, I shared a printed copy of each participant's individual interview transcription with them and asked them to check the transcription for accuracy, as well as any additions or deletions that needed to be made. After receiving positive feedback from each participant, I confirmed that no changes to the transcripts were necessary. Once the transcriptions were complete, I read and re-read the texts, engaging in "close and repeated listenings" of the interview audio recordings, making notes all the while, to "gain insights that in turn shape[d] how [I] chose to represent an interview narrative" (Riessman, 1993, p. 60) in the final research text. Mishler (2003) explained that "how we arrange and rearrange the text in light of our discoveries is a process of testing, clarifying and deepening our understanding of what is happening in the discourse" (p. 318).

In addition to the transcripts of the semi-structured interviews, I also examined the field notes that I recorded during my observations and the reflective journal that I kept throughout the research process (Appendix F), as well as the documents and artifacts provided by Trudy's family, and Trudy's six-week, self-recorded audio-visual journal. Field, interim, and final research texts are the result of "collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus" (Clandinin & Connelly, 2000, p. 20). While engaging in multiple readings of the interview transcripts and repeatedly listening to

the audio-recordings, I began making notes when phrases or ideas were repeated multiple times in the same interview and across interviews. Then, I examined the noted statements in and across the interviews to check for similarities and differences, like the constant comparison method proposed by Glaser and Strauss (1967). A pattern began to emerge across my notes, the interviews, observations, documents and artifacts and Trudy's audio-visual journal.

Due to the copious amount of research texts generated by qualitative inquiry, I originally planned to upload digital copies of all transcriptions into Atlas.ti (Version 7), a qualitative data analysis software (QDAS) program, to aid in the identification of possible recurring themes and to organize research memos. However, I decided to manually sort through the interview and audio-visual journal transcripts, as well as the documents and artifacts to generate themes. Lincoln and Guba (1985) proposed a method of generating themes by identifying quotes or expressions that fit together and then grouping those quotes and expressions by themes. Prior to data collection, I took an a priori approach to this study by beginning with three themes developed from theory and attempted to generate those themes from the questions crafted for the interview protocols for each participant. To assess whether the developed themes were relevant and evident in my study, I adopted Lincoln and Guba's (1985) method of cutting and sorting, in which the authors proposed cutting out quotes from interview transcripts and gluing them to index cards to be sorted into themes. Rather than using index cards, I began by digitally cutting and pasting quotes from my participants' interviews, which expressed similar ideas into a Word document. Then, I scanned copies of the field notes taken during my observations, as well as printed transcripts of Trudy's audio-visual journal and relevant pages from the documents and artifacts I collected to a digital, password protected file. Eventually the Word document containing the grouped interview quotes, as well as the digital copies of my field notes, Trudy's

audio-visual journal transcripts and the relevant pages of the documents and artifacts I had collected were printed, sorted into similar groups and labeled with the themes I began with through the a priori approach. Outlying information was examined, and it was determined that all relevant information had been categorized into three solid themes for this study. I used an a priori approach and created enumeration charts (Appendices O, P & Q) based on repeated words and phrases across transcripts, field notes, documents and artifacts to identify those most appropriate for this narrative inquiry.

With transcriptions, field texts and notes in hand, I began to place Trudy's story in a chronology that reflects her life history, identifying the stories and epiphanies that are most central to this study and related to the central phenomenon of resilience (Riessman, 1993; Riessman, 2008). Finally, I have presented Trudy's life history through narration that reflects the unique features of her life (Riessman, 1993; Riessman, 2008), in the hope of "creating a research text that allows audiences to engage in resonant remembering as they lay their experiences alongside the inquiry experiences, to wonder alongside [Trudy and me] who were part of the inquiry" (Clandinin, 2013, p. 51).

### **Trustworthiness**

Trustworthiness in qualitative research "is tied directly to the trustworthiness of the person who collects and analyzes the data – and his or her demonstrated competence. Competence is demonstrated by using the verification and validation procedures necessary to establish the quality of analysis" (Patton, 2002, p. 570). Similar to validation in quantitative research, trustworthiness in qualitative research addresses credibility, dependability, confirmability, and transferability, which Lincoln and Guba (1985) refer to as the "naturalists'

equivalents” for “internal validation, external validation, reliability, and objectivity” (Creswell, 2013, p. 246). According to Riessman (1993):

We can provide information that will make it possible for others to determine the trustworthiness of our work by (a) describing how the interpretations were produced, (b) making visible what we did, (c) specifying how we accomplished successive transformations, and (d) making primary data available to researchers. (p. 68)

In the following subsections, I discuss how credibility, dependability and confirmability, and transferability applies to this study.

### **Credibility**

The accuracy to which the findings describe reality is an important piece of establishing trustworthiness in a qualitative study. Credibility is strengthened by the richness of the information gathered and the analysis of the information. To establish credibility in this narrative life history, triangulation of data was essential. Triangulation “involves corroborating evidence from different sources to shed light on a theme or perspective” (Creswell, 2013, p. 251). I have accomplished this through the analysis of the data collected from interviews, observations, and documents during the research study. Member checks are “the most critical technique for establishing credibility” (Creswell, 2013, p. 252). I asked Trudy and secondary participants to review a summary of my written report and interview transcripts for accuracy, as well as omissions, thus providing a strong sense of credibility. Trudy, and each of the secondary participants confirmed the accuracy of the interview transcripts and agreed with the information provided in the written report.

### **Dependability and Confirmability**

Similar to reliability in quantitative studies, dependability refers to the inquiry process and the researcher's "responsibility for ensuring that the process was logical, traceable and documented" while confirmability "calls for linking assertions, findings, interpretations and so on to the data in readily discernable ways" (Schwandt, 2015, p. 309). An external auditor who holds a doctoral degree and who has published a narrative dissertation, was utilized in this study "to examine both the process and the product of the account, assessing their accuracy" to determine "whether or not the findings, interpretations, and conclusions are supported by the data" (Creswell, 2013, p. 252).

### **Transferability**

Another aspect of qualitative research, transferability refers to the possibility that the findings in one setting may be applicable in another setting (Creswell, 2013). Thick, rich description of Trudy's life history was utilized in this narrative study so that readers can make decisions regarding the transferability of the findings (Clandinin, 2013; Riessman, 1993; Riessman, 2008).

### **Ethical Considerations**

Clandinin (2013) stated, "narrative inquiry is a deeply ethical project . . . relational ethics call us to social responsibilities regarding how we live in relation with others" (p. 30). Therefore, it was important to account for all ethical concerns prior to and that may have arisen during the course of the research study. IRB approval was obtained prior to beginning data collection for this study. In addition to Trudy's explicit consent for others to share information about her with me, informed consent for Trudy and all adult secondary participants, as well as informed assent for Trudy's teenaged sister, as a secondary participant, was obtained prior to beginning data collection. The purpose of the study and how the data will be used was discussed

with Trudy and others involved in the research, as well as the voluntary nature of the research and the right of participants to withdraw. Confidentiality was provided using pseudonyms for names and sites. Data has been secured through password protected digital files and locked paper files. The secured data will be kept for a minimum of three years, after which time all digital files will be erased and all paper files will be shredded. The sensitivity of the information was respected by having a parent/guardian/counselor on call. I made every effort to avoid re-traumatization for Trudy, as well as any secondary participants. Since the trauma occurred at such a young age for Trudy, she has no memory of the actual trauma, however, she is aware that she is a survivor of an abusive head trauma. She and her family have lived with the effects of the trauma daily since it occurred when she was five months old. All information has been reported honestly. I have avoided reporting information that would harm participants and I have also avoided conflicts of interest (Creswell, 2013).

### **Summary**

Chapter Three includes a discussion of the research design, research questions, setting and participants involved in the current study. The selected design is a narrative life history, as the purpose of the study is to provide a voice to Trudy, an adolescent survivor of an abusive head trauma. Secondary participants' voices provide a fuller and richer description of Trudy's lived experiences. Procedures are discussed so that replication of the study would be possible including: the researcher's role, data collection, including interviews, observations, and documents, and a video journal. Data analysis, through the identification and organization of themes and a chronology to reveal an in-depth picture of the life history of the participant is included, as well as a discussion of trustworthiness and ethical considerations.

## **CHAPTER FOUR: FINDINGS**

### **Overview**

The purpose of this narrative inquiry was to describe the life history of an adolescent survivor of an abusive head trauma in the Southeastern United States. This chapter is somewhat of a departure from the typical dissertation manuscript form in that this is the life history of the primary participant, Trudy, and as such, I focused on her story as a survivor. Chapter Four begins with an introduction of the secondary participants, who are identified by pseudonyms and include Trudy's family members, a family friend, a teacher and Trudy's church youth leader. Interviews with the secondary participants and Trudy, observations, examination of written documents and artifacts, and an audiovisual journal composed by Trudy allowed me to develop a thick, rich description of Trudy's life history as an adolescent survivor of an abusive head trauma. Through careful analysis of the data, I identified themes related to Trudy's life history, including challenges she has faced, resilience mechanisms she has utilized to cope with survival and Trudy's advice to other adolescent survivors of an abusive head trauma, which are discussed on the following pages. This chapter concludes with a summary of the findings of this study.

### **Participants**

The sample included the primary participant, Trudy, and nine secondary participants, including Trudy's family members, a family friend, a special education teacher and a youth leader at her church. Secondary participants were identified by Trudy and her mother based on their relationship with Trudy. Since the focus of this study is the primary participant, a snapshot of each secondary participant was composed based on data obtained from semi-structured interviews, observations, and artifacts, including photographs, while a thicker, richer description of Trudy's life history emerged from the data collection and analysis.

## Secondary Participants

Table 3 provides a brief introduction to each of the secondary participants involved in this study.

Table 3

### *Secondary Participants and Their Relationship to Trudy*

Participant*	Age	Relationship to Trudy	Duration of Relationship
Kirsten	34	Mother	Life
Karly	16	Sister	Life
Waylon	37	Step-Father	12 years
Keith	35	Adopted Father	18.5 years
Jay	60s	Grandfather	Life
Sue	50s	Step-Grandmother	10 years
Christy	34	Family Friend	Life
Vicki	60s	Church Youth Leader	6 years
Ms. Smith	Late 20s	Teacher	2 years

\*Participants are identified by pseudonyms to maintain confidentiality.

## Trudy

In many ways, Trudy seems like any other high school girl, concerned with having friends, gushing about her boyfriend, going hiking and camping with her family, and preoccupied with wanting to drive. She loves “listening to music, watching movies, and looking at picture books (photographs of her and her friends)” and she describes herself as “beautiful, a child of God, and a Christian” (Trudy, interview, July 10, 2017). Trudy’s family and friends describe her as “her mama made over, funny, and just the sweetest” (Christy, interview, July 1, 2017), “a pretty good, outgoing girl” (Keith, interview, June 16, 2017), “absolutely precious, absolutely full of joy and life and giggles” (Vicki, interview, June 24, 2017), “a pretty smart little cookie” (Jay, interview, June 17, 2017), “loving, full of personality, very self-confident” (Sue, interview, June 17, 2017) and “nothing really bothers her and she has fun, enjoys herself and just lives” (Waylon, June 29, 2017). However, Trudy is anything but your typical teenaged girl.



Trudy is a 19-year-old survivor of an abusive head trauma that occurred when she was five months old at the hands of her biological father. What follows is a narrative of her life history told by Trudy and those who love her.

**Before.** Trudy's 16-year-old mother, Kirsten suffered from maternal toxemia during her pregnancy. As a result, Trudy made her grand entrance into this world three weeks prematurely on September 16, 1997, with a birth weight of only five pounds and 10 ounces. It seemed that Trudy would learn to be a survivor from the very beginning. After being discharged from the hospital, Trudy was developing into a "normal, healthy child" (Kirsten, interview, July 5, 2017). Just two months later in December 1997, Trudy, her mother and Trudy's biological father were involved in a car accident when a driver ran a red light and hit Kirsten's car on the passenger side, where she was in the front seat and two-month old Trudy was strapped into her car seat in the backseat behind her mother. Kirsten, who was injured, recounted that the Emergency Medical team had placed Trudy, still in her car seat, into the back of the ambulance to be transported along with her mother to the hospital and that Trudy "just stopped breathing" (Kirsten, interview, July 5, 2017). The Emergency Medical Team immediately turned their attention to Trudy and were able to resuscitate her in the ambulance. Upon arriving at the hospital, a CT scan revealed that Trudy had incurred a trauma to her head, which was causing a build-up of blood and fluid around her brain, as well as a pulmonary contusion (bruising of the lungs), and a fractured rib (Appendix H). At that time, Trudy underwent a surgical procedure to relieve the fluid on her brain and she was hospitalized in the Pediatric Intensive Care Unit for a period of approximately two weeks (Kirsten, interview, July 5, 2017). During this hospitalization, Trudy experienced a seizure and was placed on medication to help control future occurrences "as a precaution" (Kirsten, interview, July 5, 2017). After a brief recovery, Trudy

seemed to be “fine, she was doing everything she was supposed to be doing” (Kirsten, interview, July 5, 2017).

**If it was just accidents, I don’t know.** Though Trudy’s parents were not married, they had been living together with Trudy in a basement apartment at her paternal grandparents’ home. After the car accident, Kirsten “had to drop out of school” because she had missed so many days that she would not be able to receive any high school credits (Kirsten, interview, July 5, 2017). However, Kirsten wanted to complete her education and so she enrolled in a night school program that allowed her to earn credits towards a high school diploma, which left an infant Trudy in the care of her seventeen-year-old biological father. Kirsten recalled an instance in which Trudy’s bottom was very red and when she questioned Trudy’s biological father about it, he said that “his grandma dropped her on the floor” and when she questioned the grandmother about the incident, the grandmother agreed that Trudy had slipped out of her hands and fallen a short distance to the floor, where she landed on her bottom (Kirsten, interview, July 5, 2017). Kirsten did not pursue the incident further because she believed it was an accident and Trudy “seemed fine” (Kirsten, interview, July 5, 2017). In another recollection, Kirsten noticed that Trudy “had a little black place on her eye” and that Trudy’s biological father told her that “the screen door hit her” at his father’s house (Kirsten, interview, July 5, 2017). Again, when Kirsten asked Trudy’s paternal grandfather about the incident, he confirmed the story. Kirsten’s step-father, Jay, revealed that doctors had noted that in addition to the broken ribs Trudy sustained in the car accident that there were other “ribs that had been broken and were mending” that Trudy’s family had not been aware of prior to the car accident (Jay, interview, June 17, 2017). Kirsten stated that looking back, “if it was just accidents, I don’t know. I just think that you know, was those things that he had actually done?” (Kirsten, interview, July 5, 2017).

**Something wasn't right.** On February 3, 1998, Kirsten was attending a class in her night school program when her mother showed up and told her that Trudy had been taken to the hospital and that “she had had a seizure” (Kirsten, interview, July 5, 2017). Kirsten’s recollection of the events of that night follow:

When I got to the hospital, [Trudy] was naked, I mean she didn't have any clothes on because [her biological father] said that he was bathing her. She was in her car seat and she didn't have any clothes on and she had bruises all over her. Umm, so automatically I knew that something wasn't right and I just started asking questions, you know, but I was also in a state of shock at that moment. But he just kept sayin' that he was, you know, that he was giving her a bath and she had a seizure and slipped out his hands. I just kept waitin' for the doctors to tell us something, but you know, it was actually probably a day later before they gave me any real details, as to you know, what had happened (Kirsten interview, July 5, 2017).

Trudy's biological father, who had brought her into the hospital's emergency room, had just turned 18 years old. Kirsten stated that he “just kept cryin' and sayin' that he didn't know what had happened, that she had just, that she had had a seizure” and she even remembered that his uncle, who was a fireman, had looked at him and asked him “what did you do to that baby?” but even those words “didn't register” until the doctors asked to speak with her alone in a conference room to discuss Trudy's injuries (Kirsten, interview, July 5, 2017). Doctors confirmed Kirsten's worst fears, that five-month-old Trudy had been “subjected to shaken baby syndrome. As a result, she sustained a fractured skull, bilateral cerebral hemorrhages, and bilateral retinal hemorrhages with retinal detachments” and that she would undergo “surgery to relieve the bilateral cerebral hemorrhages” (Appendices G & H).

**He confessed.** Kirsten had been required to attend a teen parenting class in order to stay in high school while she was pregnant with Trudy, during which she was informed about shaken baby syndrome and strategies to cope with infant crying. When doctors began to tell Kirsten about Trudy's injuries, she said that she "knew exactly what had happened" (Kirsten, interview, July 5, 2017). Trudy's biological father was not required to attend those classes. After speaking with doctors, Kirsten and Trudy's biological father were both questioned at the hospital by detectives regarding what had happened to Trudy. The following morning, detectives asked Trudy's biological father to accompany them to the police station. Hours later, the detective returned to inform Kirsten that Trudy's biological father had "confessed to what he had did and that he said that she was umm, she was cryin' and that he umm, he choked her, shook her and threw her to the floor" (Kirsten, interview, July 5, 2017).

**This little light.** After being hospitalized for one month, Trudy was prescribed several medications to control seizure, reflux and pain and discharged to Kirsten, who after discontinuing the relationship with Trudy's biological father moved in with her parents so that she could continue to attend night school in the hopes of finishing her education. Upon returning home, Trudy began receiving both physical and occupational therapy services in her home. At her six-month checkup, Trudy's medical records indicated that the retinal detachments she suffered as a result of being shaken had resulted in "probable blindness" (Appendix I). Kirsten and her parents were also convinced that Trudy was blind and echoed this concern multiple times to Trudy's medical team. Trudy's ophthalmologist had indicated that the likelihood of a successful surgery to reattach her detached retinas was highly unfavorable since she had suffered such severe damage (Kirsten, interview, July 5, 2017) and her doctors "thought she'd never see . . . they thought she was gonna be totally blind" (Jay, interview, June 17, 2017). Shortly after this

determination was made, a vision therapist began to work with Trudy and had even begun to discuss teaching her to read braille. After about three months, when Trudy was nine months old, the vision therapist told Kirsten that Trudy “can see something” and she told her that she was going to bring “this little light box” into the next therapy session to see how Trudy would respond (Kirsten, interview, July 5, 2017). Kirsten recalled

Well, she brought it out and it projected colors and shadows on the wall. Sure enough, [Trudy] was following that and I’m like you’re crazy. So, I called the doctor and I remember thinking the he must think I’m crazy, umm but he set us up an appointment. I took her in and I remember him, I remember that day ‘cause he just kinda set there and looked at me and umm, he told me. He told me, he said “Kirsten, I don’t know how this happened because it should not be possible,” but he said that her retinas had partially reattached themselves. (Kirsten, interview, July 5, 2017)

It seemed that a miracle had occurred and even though Trudy is still considered legally blind, she does in fact have some eyesight. In 2002, six-year-old Trudy underwent eye surgery to strengthen the muscles in her left eye to keep the eye from drifting inward, but that has not completely corrected the problem. Trudy also began to wear glasses, but they are more for protection than for vision correction.

**Rehabilitation.** At 11 months old, Trudy began to attend the Merry Center\* for children with special needs. This pre-school environment provided Trudy with programs in occupational, physical, and speech-language therapies in addition to a pre-school educational program. When Trudy entered the program, her fine motor abilities were measured using the Peabody Developmental Motor Scales, which revealed that her basal age was in the six-seventh month old range, even though she was 11 months old (medical record, August 24, 1998). As a result, Trudy

began to engage in 30-minute occupational therapy sessions once per week and 30-minute physical therapy sessions twice per week (medical record, August 24, 1998). With the help of the occupational therapists, Trudy began crawling by December 1998 and by February 1999, she was walking (Kirsten, interview, July 5, 2017). At one year old, Trudy's language skills were measured utilizing the Rosetti Infant-Toddler Language Scale, which revealed that she exhibited mild-moderate delays in language skills and mild deficits in oral motor functioning (medical record, September 1998). As a result, Trudy began to engage in speech-language therapy one to three times weekly for 30 to 60-minute sessions (medical record, September 1998). The Merry Center provided Kirsten with Trudy's first Individualized Education Program in 1998 (Appendix J) and set annual goals for Trudy regarding her education, occupational, physical, and speech-language therapies.

**Pre-School.** By the time Trudy was eight months old, Kirsten, still a teenager, had begun a relationship with a young man named Keith, whom she had known in high school. Keith was committed to both Kirsten and Trudy and after a few months of dating, Kirsten and Keith were married and in July 2000, Keith adopted two-year-old Trudy, who has always referred to him as Dad. Trudy's little family expanded on November 25, 2000, when her baby sister Karly was born. Trudy was still attending pre-school at the Merry Center and her teachers commented that she was a "very personable and friendly child, who enjoys learning activities and interaction with other children and exhibits determination in all that she is presented with" (IEP, November 10, 2000). Though she had made some progress, Trudy's therapists and teachers noted in her IEP that she had "delays in communication, visual perceptual, and fine motor delays that would affect her progress in the general curriculum" at the time (IEP, November 10, 2000).

**Elementary school.** In August 2002, five-year-old Trudy started attending public school and was enrolled in a general education curriculum for kindergarten. After entering kindergarten, Trudy was evaluated by the special education department in her school district and a determination was made that she needed accommodations in the classroom. Placing Trudy in a class for students with special needs meant that she would have to transfer schools since only one elementary school in Trudy's school district served students with emotional and neurological disabilities. Trudy's kindergarten teacher was "really good and she just had a lot of patience, and worked with [Trudy] on her level in that class until she could move schools the following year" (Kirsten, interview, July 7, 2017). Trudy began first grade with an IEP in place and her teacher indicated that while she seemed to be progressing towards her academic goals, she showed slower progress in meeting her goals in regard to classroom behavior and social skills, such as remaining on task during independent and group work and refraining from attention-seeking behaviors, although her teacher still viewed her as "a delight" to work with (IEP, September 4, 2004). Throughout elementary school, Trudy suffered seizures and was diagnosed with Attention Deficit/Hyperactivity Disorder (ADHD), so she was placed on a series of medications to help control both. By the end of 2004, when Trudy was seven years old, Trudy's mother, Kirsten and her adopted father, Keith had decided it would be best for their family for them to divorce. The divorce was amicable, and Kirsten and Keith agreed to remain friends and to co-parent Trudy and her sister, Karly in order to transition the girls as easily as possible to this new life with their parents no longer under the same roof.

**Trudy's bonus dad.** A year after her divorce, Trudy's mother, now in her twenties, met and started dating Waylon, a hard-working, good-natured, well-liked young man who "immediately fell for" Kirsten (Waylon, interview, June 29, 2017). Kirsten waited six months

before introducing Waylon to eight-year-old Trudy and her sister. When Waylon met Trudy, he thought she “had a very southern accent and she was hilarious [laughter] and she was very bright” (Waylon, interview, June 29, 2017). Six months after meeting Trudy and her sister, Waylon and Kirsten were married. Trudy and Waylon, both known for their innate ability to make people laugh, are like “two peas in a pod” and Trudy “adore[s] Waylon,” whom she refers to as her “bonus dad” (Trudy, interview, July 10, 2017). Waylon jumped right into co-parenting, alongside Trudy’s mother and adopted dad, Keith. Trudy recalled one of the best memories she had of that year, besides gaining “another dad” was “going on a trip to Disney with her Dad [Keith] and her Meme [Keith’s mother]” (field notes, May 27, 2017). Though Trudy’s family life was stable and happy, and she seemed to be enjoying school, at the start of her 5th grade year, Trudy was referred by her neurologist to a clinical psychologist “for a neuropsychological evaluation secondary to concerns of regression in neurocognitive functioning” (medical record, August 9, 2007). The evaluation revealed that Trudy displayed a range of deficiencies, and that “domains which were relative strengths when she was tested in 2003 appeared to be less functional during this examination” (medical record, August 9, 2007).

**Middle school.** By the time she entered 7th grade, 12-year-old Trudy was spending the majority of her day in the special education classroom, since “her cognitive functioning [was] lower than that of her same age peers in all areas of development; she [was] unable to experience success in the general curriculum” (IEP, March 10, 2010). Kirsten recalled that “sometimes they would pull her out, umm, to go to social studies or science. But it was more of a social reason, than academic, so they pulled her out to do to group stuff with those kids in those classes” (Kirsten, interview, July 5, 2017). She also still participated in the general education curriculum in her related arts classes, with non-disabled peers, except for Physical Education, which she was



not allowed to participate in “due to safety concerns” (IEP, March 25, 2010). At this point, Trudy was reading on a “first grade level” and having some difficulty “identifying coins and their values” in math (IEP, March 25, 2010). Trudy’s teachers remarked that though she was “usually well-behaved in the classroom and at school, she does not always listen to the teacher’s suggestions and wants to complete tasks her way which causes her to have difficulty learning new material as well as causing her to complete tasks incorrectly” (IEP, March 25, 2010). While Trudy “loved her middle school teacher,” she acknowledged that she had a difficult time “staying focused” on her work and that tended to cause her to become “frustrated” at times (Trudy, field notes, May 26, 2017). Her teachers also noted that Trudy “fears getting lost” when traveling around the school and that she “often has difficulty focusing on completing one task at a time” (IEP, March 25, 2010).

**Trudy, the athlete.** While in middle school, Trudy’s family wanted to help her build some self-confidence and encouraged Trudy to find a hobby that she would enjoy. During her 6th grade year, 11-year-old Trudy began competing in the Special Olympics and playing baseball for the local Miracle League, which she has continued throughout her middle school and high school years. Trudy’s younger sister, Karly is a soccer standout, so playing baseball has helped to “boost [Trudy’s] confidence and helps her to feel good about herself” (Keith, interview, June 16, 2017). Her bonus dad, Waylon swelled up with pride as he described Trudy’s “accomplishments in the Special Olympics; she’s won gold a couple of times in the 100-meter dash and I was very impressed by that” (Waylon, interview, June 29, 2017). Trudy “is very relational” and has benefited from “being part of a team because she has achieved so much” (Sue, interview, June 17, 2017). Trudy describes baseball as “her thing” and she has “made a lot

of friends and met her boyfriend” through her participation on the baseball team (Trudy, interview, July 10, 2017).

**Transitioning to high school.** Towards the end of her 8th grade year, when Trudy was 14 years old, her teachers met with her mother to inform her of Trudy’s options regarding completing high school, as transition planning is mandated by the reauthorization of IDEA (2004). Kirsten was informed that though Trudy would not be eligible to earn a high school diploma, she did have other options which would prepare her for the future after high school. Kirsten recounted that “we pretty much knew that she would be able to get at least an occupational diploma, if that’s what we wanted, you know, if that’s what we thought she wanted to do or we could let her get a certificate” (Kirsten, interview, July 7, 2017). The certificate provides proof that a student attended high school for four years and participated in a special education program while there. While the occupational diploma requires students in a special education program to meet minimum attendance requirements established by the school board, complete 24 required course units, 30 hours in a computer lab, 20 hours of community service and gain 360 hours of work experience, which can be a combination of paid employment and on/off campus job training (Appendix K). After much consideration and prayer, Trudy and her parents elected for her to earn an occupational diploma. Up to this point, this program has not been recognized state-wide in South Carolina, where Trudy resides, however, there is currently a bill being voted on in the South Carolina House of Representatives to do so.

**Trudy learns the truth.** Although Trudy was previously aware that she had disabilities, she was unaware of how she had incurred them. Between her 9th and 10th grade year, Trudy’s mom, Kirsten and Trudy’s adopted father, Keith decided to tell her the truth about what had happened to her as a baby. Keith and Kirsten explained to Trudy that Keith had adopted her and

raised her as his own daughter and that her biological father “wasn’t a nice person and that he had hurt [Kirsten] and hurt [Trudy] and he just could not be around anymore” (Kirsten, interview, July 5, 2017). Since then, Keith said that he and Kirsten have told Trudy “on several occasions about what happened, and it just seems like she doesn’t remember that part” (Keith, interview, June 16, 2017). During our interview, Trudy told me that her mom told her what had happened to her when she was around 16. When I asked her how that made her feel, Trudy said “I cried a few times. I still do it now ‘cause I’m at church and I’m just sitting there thinking did that really happen, when I’m supposed to be paying attention, but I just sit there sometimes, and it just comes, I mean I don’t know. I feel sad and I cry sometimes” (Trudy, interview, July 10, 2017).

**High school.** When Trudy entered her 9th grade year in 2012, she transitioned to Green High School, where she could receive services in a self-contained classroom for students with Neurological Disabilities. During her freshman year, 15-year-old Trudy didn’t enjoy school because she disliked her teacher, who she characterized as unfair and expressed that “he would get mad” at her and her classmates “for no reason whatsoever” (Trudy, interview, July 10, 2017). While discussing this teacher’s behavior, Trudy kind of snickered and said, “I didn’t like it, so I’m sorry God, just help me not to be mad at this teacher” (Trudy, interview, July 10, 2017). Needless to say, Trudy’s freshman year was tough and much of her frustration at school would manifest itself at home in the form of anger and crying and her mother felt that “the kinds of stuff she would get emotional and cry about, I don’t think most kids would” (Kirsten, interview, July 7, 2017). At the beginning of her sophomore year of high school, Trudy was assigned to her current teacher, Ms. Smith, who was young and energetic and who Trudy enjoyed and trusted. Ms. Smith has worked with Trudy in a self-contained special education classroom for the past

two-years. Trudy “currently reads on a 3rd grade reading level and continues to struggle with adding mixed amounts of money” (Ms. Smith, interview May 22, 2017). Though she struggles academically, Trudy “is kind to everyone and makes everyone laugh. She has many friends in the self-contained classroom and in the general education classes” (Ms. Smith, interview, May 22, 2017). One of the general education classes Trudy had was PE. When I asked her if she enjoyed that class, she erupted with laughter and said:

I don't really do much in there, umm, don't tell my mother, umm, my legs get tired. So I go and set down [laughing], which my teacher lets me and all the other kids are lined up against the wall like this (makes a motion like they're all looking at her like what gives?) and I'm like “what's up y'all? How y'all doing?” (laughing hysterically). (Trudy, interview, July 10, 2017)

In difficult situations, Ms. Smith expressed that Trudy previously would “sometimes become frustrated, which at times lead to inappropriate behaviors, such as yelling or crying,” however, “this behavior had greatly decreased this school year” (Ms. Smith, interview, May 22, 2017). Trudy agreed with Ms. Smith's assessment of her growth and admitted that she “used to get pretty frustrated, but now she doesn't get that frustrated anymore” when she encounters things that are difficult for her (Trudy, interview, July 7, 2017). Trudy also “handles criticism from adults much better this year,” which is important since she has to complete job training experiences outside of her school environment in order to earn an occupational diploma (Ms. Smith, interview, May 22, 2017).

**Job training.** As part of her occupational diploma program, Trudy has participated in job training for half of her sophomore year and all of her junior year. While on a camping trip over Memorial Day weekend in 2017, with Trudy and her family, she discussed her job training

experiences with me. Trudy's first job training experience, outside of her school, was at a daycare. Her teacher, Ms. Smith told me that Trudy was placed at the daycare because Trudy "thought she wanted a job like this after high school" (Ms. Smith, interview, May 22, 2017). However, Trudy expressed to me that "she didn't like working at the daycare because she didn't know any of the adults there" (Appendix D). Ms. Smith revealed that she was "glad that [Trudy] realized this was not the best job for her after high school" (Ms. Smith, interview, May 22, 2017). Trudy's next job training experience was at a charity thrift store. Accompanied by a Teacher's Aide and two other students, Trudy worked at the thrift store from 9:00-11:30 AM on Tuesdays and Thursdays and her job entailed "sorting and labeling books according to genres, sorting hangers and sometimes sorting clothing" (Ms. Smith, interview, May 22, 2017). During our walk, Trudy told me that she "likes [working at the thrift store] because she likes to sort things," however she did not enjoy sorting clothing because "she can't see well enough to see the sizes or the stains on the clothing" (Appendix D). Ms. Smith feels that the job training experience has created "more interest in having a job after high school [for Trudy] and has bolstered her confidence in her job skills and independent functioning skills," which is the point of the occupational degree (Ms. Smith, interview, May 22, 2017).

**Trudy, the college student?** Trudy's sister, Karly is graduating from high school next year, so Trudy's family had planned for Trudy to remain in high school for one more year so that she could finish high school with her sister. Even though Trudy is 19 years old, students in the Trudy's home state may remain in high school until age 21, if needed. While Trudy's sister, Karly is heading to the West coast after graduation to engage in a two-year mission work program, Trudy's postsecondary future had not yet been determined. Knowing that Trudy had one more year of high school at most, her teachers and parents began to examine programs that

would allow her to transition to life as an adult. One of the programs that Trudy and her parents explored was the LIFE Program, which is available on two college campuses in Trudy's home state. This tuition-based program allows students, like Trudy, who have mild to moderate intellectual and/or developmental disabilities to experience some aspects of college life, while living on campus for four years in a specialized set of dorms and learning independent living skills such as "keeping an apartment, using public transportation, cooking meals, and using a budget for purchases" (Ms. Smith, interview, May 22, 2017). Trudy, her mother, and bonus father, along with her adopted father visited one of the college campuses and met with the director of the LIFE program, as well as some of the students in the program. Though the meeting was very informative, Trudy and her family had mixed feelings regarding the program and whether it was the right fit for Trudy. Her mother, Kirsten and step-father, Waylon, and even her sister, Karly felt very encouraged about the "opportunity to grow and learn to become more independent" that the LIFE program could offer Trudy (Karly, interview, June 28, 2017). Trudy's adopted father, Keith expressed his concern for Trudy moving away from home "Do I have doubts? Yes, I do you know? Do I, do I believe that she can do it? Yes, I do, so it's kinda mixed emotions about that" (Keith, interview, June 16, 2017). Trudy's grandfather agreed that the visit and the idea of Trudy moving away to live on a college campus "gave that baby anxiety" (Jay, interview, June 17, 2017). Trudy and I had a long discussion about her visit to the college and she explained her feelings to me like this:

Mom even asked me this "are you gonna go to whatever that college is called?" I'm like naw, ugh, uhh uhh, noooo. That's why I didn't want to get into it. Like I didn't want to get into the program. I didn't want to get accepted, so I prayed for the other one instead. It's like my heart's just not in it. (Trudy, interview, July 10, 2017)

Trudy has made up her mind that she does not want to be a part of the LIFE program due to her fear of living away from her family and her parents have come to accept that, at least for now, college is not a part of Trudy's plan for her life after school. This realization did leave Trudy and her family hopeful that "God would open another door" for her (Kirsten, interview, July 7, 2017).

**Project SEARCH.** In trying to help Trudy and her family examine options for her transition from high school, Trudy's teacher, Ms. Smith, became aware of a new program available in her school district called Project SEARCH, which offers students who have disabilities the opportunity to experience a year-long workplace immersion program in a major hospital system in Trudy's city. As part of the high school transition program, students spend their first few weeks participating in new employee orientation, getting used to the hospital environment and the expectations of being an employee. Throughout the remainder of the school year, students spend approximately one hour per day in class learning employability and functional skills. Students also experience three rotations during their internships, which provides the opportunity to train in three different areas of the hospital doing three different jobs. At the end of the internship, successful interns are hired by the hospital system. After gaining permission from Trudy and her mother, Trudy's teacher, Ms. Smith nominated her for the highly competitive program. With the help of Ms. Smith and the support of her family, Trudy completed the application and interview process. In May 2017, Trudy and her family's prayers were answered when Trudy was informed that she had been accepted to the program (Appendix M). Trudy is very excited and looking forward to "working at the hospital as long as [she] can" (Trudy, interview, July 10, 2017). On May 26, 2017, Trudy had her final IEP meeting and was provided with a copy of her final IEP (Appendix N), which indicates that she will complete the

requirements to earn her occupational diploma in the coming school year and that she will “be prepared for employment in her community in the field of Human Services.” Trudy and her family are very encouraged about what her future holds.

## **Results**

During this research study, I collected data through semi-structured interviews, observations, documents and artifacts, and an audio-visual journal recorded by the primary participant. The following section includes a discussion of the results of this study. Theme development is discussed, and research questions are answered, in the context of three generated themes.

### **Theme Development**

Semi-structured interviews were conducted with one primary participant, Trudy, and nine secondary participants, including Trudy’s mother, step-father, adopted father, 16-year old sister, grandfather and his wife, Trudy’s mother’s long-time friend, Trudy’s youth leader at her church, and Trudy’s teacher. Through data analysis, I generated three themes that fit the aims of my research questions (Appendix O). The three themes I identified are as follows: (a) challenges, (b) resilience/coping mechanisms, and (c) advice. Several sub-themes were also generated within the themes of challenge (Appendix P) and resilience/coping mechanisms (Appendix Q). Each of these themes and sub-themes will be discussed in the context of the research questions that guided this study below.

### **Research Question Responses**

The central question guiding this study was what are the lived experiences of an adolescent survivor of an abusive head trauma in the Southeastern United States? Through information collected from semi-structured interviews with the primary participant, Trudy and



secondary participants, as well as data collected through observations, studying relevant documents and artifacts provided by Trudy and her family, and a six-week audio-visual journal maintained by Trudy herself, I have worked in conjunction with Trudy and her family to present an accurate and honest portrait of her life history as an adolescent survivor of an abusive head trauma in the Southeastern United States. An innocent baby, at the age of five months old suffered an abusive head trauma that changed her life forever. Throughout her life, as a survivor, Trudy has faced many challenges that have affected her neurological, cognitive, behavioral, academic and social development. In the face of those challenges, Trudy has developed resilience mechanisms, such as a large support network, adaptive behaviors, faith and perseverance that have allowed her to cope with life as a survivor of an abusive head trauma. Though her life has not taken her down conventional roads, her future is full of promise and purpose. What follows is a discussion of her very important life situated in the context of the research questions and the themes that emerged from her survival.

### **Sub-Question 1: Challenges**

What challenges does an adolescent survivor of an abusive head trauma face? (RQ1). A common thread in all of the semi-structured interviews, observations, documents and artifacts, as well as the audio-visual journal maintained by Trudy during the study revealed that Trudy faced various and numerous challenges throughout her life as a survivor of an abusive head trauma. Many of the participants, including Trudy herself, expressed that Trudy had encountered many difficult or hard situations that caused a great deal of frustration and anger for her. In examining the data, several sub-themes emerged regarding the challenges that Trudy has faced, including: (a) neurological, (b) cognitive, (c) behavioral, (d) academic, and (e) social. These sub-themes

are used to describe the challenges that Trudy has faced as a survivor of an abusive head trauma in the passages that follow.

**Neurological challenges.** Regarding neurological challenges, Trudy experiences seizures and vision impairment, as well as having experienced impaired walking, and delayed gross and fine motor skills at various points in her life. Trudy experienced her first seizure in the Pediatric Intensive Care Unit following a craniotomy to relieve the bilateral cerebral hematomas she suffered as a result of the abusive head trauma she incurred at five months old (Appendix I). Trudy continued to experience seizures of various degrees of intensity throughout her childhood and was diagnosed with Complex Partial Seizures with Todd's Paralysis by age nine (medical record, August 9, 2007). During a semi-structured interview, Trudy's mother, Kirsten described Trudy's experience with seizures:

Umm, she had a couple Grand Mal seizures when she was little. Umm, and one of them she actually stopped breathin' and then they had to put her in the hospital. Umm, and then the other one, they took her to the hospital and they sent her home. So she's only had a few like really, really bad ones. Umm, and most of them now, like she's had in the last few years, she kinda just sits there and stares, which is kinda hard cause she does that sometimes anyways. She don't, like she, if you try to talk to her, she won't really respond, so those are the ones she's kinda had, you know, I would say in the last five years. That's kinda been how they are. (interview, July 5, 2017)

When I asked Trudy about her experience with seizures, she told me that she "kinda knows [when a seizure is about to happen] and she just don't feel right" (interview, July 10, 2017).

Trudy's seizures have been controlled through a series of medications over the years. As Trudy has grown and developed, these medications had to be adjusted to meet her needs. Trudy's

current prescription has to be taken twice daily, every day. This medication has allowed Trudy to experience fewer seizures over the years and she has gone as long as four years without experiencing a seizure (Kirsten, interview, July 5, 2017). In addition to seizures, another neurological challenge that Trudy faces is vision impairment.

***Vision impairment.*** As a result of the abusive head trauma that Trudy suffered, she experienced bilateral retinal hemorrhaging with retinal detachments (Appendix H). Due to the detachment of her retinas, doctors were uncertain how much sight Trudy would regain, if any (Appendix H). Currently, Trudy's vision is "20/100 in her right eye and 20/200 in her left with her glasses appropriately correcting for nearsightedness and astigmatism," as well as "moderate intermittent exotropia, bilateral optic nerve atrophy and a temporal macular scar in her left eye, which as are all stable" (medical record, November 23, 2016). While Trudy wears glasses full-time, Trudy's mother explained that

her glasses are more for protection. They don't really help her vision as much as it is to protect her eye. So, umm, cause if she gets an injury in her good eye, I mean she will not be able to see. (Kirsten, interview, July 5, 2017)

Trudy's mother and grandfather described Trudy's vision in her left eye as if she is "seeing through a pinhole" (Jay, interview, June 19, 2017; Kirsten, interview, July 5, 2017). Trudy's grandfather, Jay said "I mean if you'll watch her sometimes, she'll, she'll cock her head or, or move her eyes back and forth so she can find, or to line the hole up to see through it" (interview, June 19, 2017). I observed Trudy engage in the behavior that Jay described during each of my interactions with her. Trudy's step-father, Waylon added that she "has to watch TV really up close. She has to, you know, get close to everything she reads (interview, June 29, 2017). I also observed Trudy interact with various media in the manner that Waylon described as I watched

her read or play games on her iPad (field notes, June 28, 2017) and send texts on her cell phone (field notes, May 28, 2017). When I spoke to Trudy about how her vision impairment affects her life she told me a story about counting money. She said “counting the change, I don’t know I still have a hard time seeing it, yes. That’s kind of the big deal with the money, like I had a hard time seeing that” (Trudy, interview, July 7, 2017). As Trudy and I discussed her difficulty with counting change, I realized that she has come to the conclusion that she has difficulty with certain academic subjects, not because she is incapable of grasping concepts, but because her vision impairment interferes with her ability to accomplish some tasks. In the past, Trudy has also experienced impaired walking and delays in gross and fine motor skills.

*Impaired walking and delays in gross and fine motor skills.* Shortly after her head trauma, Trudy’s medical team recorded that she was unable to roll over, lift her head, or grasp for objects (medical record, February 27, 1998). The medical team also noted that Trudy needed full support while sitting and that she exhibited very poor head control when in a seated position (medical record, February 27, 1998). Trudy received occupational and physical therapies in her home for a while after she was released from the hospital, following her head trauma and her grandfather explained that “the therapists would come out to the house and they would work with her, I mean just for her to sit up and sit on her own, she was probably two years old” (Jay, interview, June 17, 2017). While those deficits improved, Trudy continued to exhibit delays at 11 months old, as a Peabody Developmental Motor Scales assessment revealed her functioning closer to seven months of age (medical record, August 24, 1998). Additionally, by 11 months of age, Trudy was not yet crawling or walking (medical record, August 24, 1998). Trudy’s mother, Kirsten’s friend explained the heightened awareness of Trudy’s delays at the time: “I mean there was a time that they said she wouldn’t see or she wouldn’t walk. I can remember her doin’

therapy and they, they would remind you, you know she might not crawl!” (Christy, interview, July 1, 2017). By the time Trudy was 36 months of age, another Peabody Developmental Motor Scales assessment placed her age equivalency at 23 months old (IEP, November 10, 2000), but by that time, Trudy had begun to walk. At age seven, Trudy continued to exhibit “poor fine motor skills and poor motor planning” (medical record, February 2004). Around that same age, Trudy had heel cord release surgery since she walked on her tiptoes, however, doctors never confirmed whether this was an effect of her head trauma or whether it would have been the case anyway like with many children (Kirsten, interview, July 5, 2017). Since childhood, Trudy’s gross and fine motor skills have improved, although she still walks on her toes from time to time. In addition to neurological challenges, Trudy has faced cognitive challenges throughout her life as a survivor of an abusive head trauma.

**Cognitive challenges.** In regard to cognitive challenges, Trudy has been impacted in the areas of language and executive functioning, specifically reasoning, organization, attention and most significantly, memory. As a one-year old child, Trudy exhibited “mild to moderate delays in language skills and mild deficits in oral motor functioning” (medical record, September 1998). By the time she was nine years old, Trudy’s “language abilities were [still] mildly impaired for her age” (medical record, August 9, 2007). Over time, Trudy has been able to experience growth in this area, as she currently reads “third grade reading passages fluently with high levels of accuracy” (IEP, February 3, 2017). Trudy’s teacher, Ms. Smith, corroborated this evidence of growth by relaying that Trudy “enjoys reading out loud in front of her peers and often volunteers to do so” (interview, May 22, 2017).

**Reasoning.** While Trudy’s language skills have grown, she has faced some difficulty in the area of reasoning. Trudy’s younger sister, Karly provided an example of Trudy’s struggles

with reasoning when she said “yea, we used to play like board games and stuff a lot and she just like didn’t grasp how to play ‘em and umm (long pause) and so it just, I don’t know, it just didn’t make sense” (Karly, interview, June 28, 2017). Trudy could not seem to understand the rules of play or how the games were won, which often led to frustration on Trudy’s part and in turn, led to her and Karly not playing together too often as younger children (Karly, interview, June 28, 2017). In addition to facing challenges in the area of reasoning, Trudy is also challenged in the areas of organization and attention.

***Organization and attention.*** At some point during third grade, Trudy’s struggles with organization and attention began to become evident to her family. Many young students face difficulty with completing homework, but Trudy’s mother stated that “just one sheet may take, you know, one math sheet may take [Trudy], you know, 30 or 40 minutes to do versus obviously another kid might could do it in 10 minutes (Kirsten, interview, July 5, 2017). Trudy’s teachers had also expressed concern that Trudy was having some trouble staying focused at school, which led Trudy’s mother to mention this concern to her doctor. As a nine-year-old, Trudy was diagnosed with Attention Deficit/Hyperactivity Disorder (ADHD) as her doctor observed “inconsistent use of organized and strategic approaches in completing tasks,” as well as limited ability to sustain focus during a neuropsychological examination (medical record, August 9, 2007). At that point, Trudy was prescribed three medications, which she continues to take daily, to regulate the ADHD, as well as to help with sleeplessness. Trudy has continued to face challenges with organization and attention, as it “can sometimes take months for her to master a new skill,” whereas someone who does not face these challenges may master new skills much sooner (Ms. Smith, interview, May 22, 2017). As previously alluded to, Trudy’s most significant cognitive challenge involves memory.

**Memory.** Trudy's short-term memory has been radically affected by the abusive head trauma that she suffered as an infant. Because of this, Trudy sometimes becomes impatient when she needs to say something and she is asked to wait. When Trudy and I discussed her difficulties with remembering what she wants to say, she said "yea, I'm not gonna remember if you don't let me tell you" if she is asked to wait (Trudy, interview, July 10, 2017). Trudy's mother affirmed that "she can remember something that happened when she was five years old, I swear, but you know she can't remember something we told her to do two minutes ago. Umm, so and she's always been that way" (Kirsten, interview, July 7, 2017). Trudy's grandfather, Jay talked about Trudy's ability to remember song lyrics, even though she struggled with short-term memory issues and I have observed Trudy recite enormous amounts of dialogue from her favorite movies or television shows during my many interactions with her, as well. During an interview with Trudy's step-grandmother, Sue, she told me a story that perfectly illustrates Trudy's challenges with short-term memory:

She kept texting me "do you have an ice pack?" I said I sure do. Well, umm, she just asked me probably 10 minutes before that if I was home? (laughter), specifically, yes, I'm home and I'm getting' ready for a couple of doctor's appointments today, what do you need? and she says "nothing, I was just checking on you." I said well, you still haven't been over to get your money, 'cause she took care of our pet, Roxy, our cat, and umm she says "I came over and saw Papa the other day," Oh, ok well did he pay you because he didn't tell me that? Did he pay you? This is all through text. She says "No I don't think so." Well I think if he had handed her \$40, she would remember that. Umm, and she says "I don't think so." I says well good because I have your money, when are you coming over? "Oh I don't know." So a few short minutes later, she says "are you

home, I need an ice pack?” So, her attention span is really, really short. Her, you know, her short-term memory is, is not good. It’s not good at all and umm, then I asked her, just out of curiosity, already knew the answer, but I asked her if she remembered how much money I owed her because I created a chart for her. She got here, couldn’t even remember that she needed an ice pack and she couldn’t even remember that she was here to get money, so (laughter). (Sue, interview, June 17, 2017)

Trudy’s teacher, Ms. Smith told me that even though her classroom intentionally operates on a routine schedule, that Trudy sometimes forgets what they typically do during a given period and will sometimes ask to be reminded of what she’s supposed to be doing (interview, May 22, 2017). Trudy’s family members are concerned about how her challenges with short-term memory are going to affect her quality of life in the future. Kirsten, Trudy’s mother, told me that one of her concerns is Trudy “working with a stove and then forgetting that the stove is on because she can’t remember stuff or you know putting a number in wrong on the microwave” (Kirsten, interview, July 7, 2017). Clearly, Trudy will continue to face new challenges concerning her issues with memory. Along with neurological and cognitive challenges, Trudy has faced behavioral challenges throughout her life.

**Behavioral challenges.** Due to the brain injuries she suffered as a result of the abusive head trauma, Trudy has experienced a range of emotional and behavioral challenges. Trudy’s behavioral challenges have manifested in a number of ways. Trudy had severe anger issues as a small child, as her mother, Kirsten explained:

I mean, her anger, well temper, I guess would just be like uncontrollable. I mean she would be to the point that I would physically have to restrain her, I mean because if not, she would throw stuff at me, she would hit me. When she was little, I mean she was



probably 3 or 4 years old and I would have to physically hold her you know so she didn't hurt somebody or hurt herself. I mean that probably started at 3 or 4, umm, when she started doing that. (Kirsten, interview, July 5, 2017)

Trudy continued to face behavioral challenges through elementary school, as her doctor noted that she "became irritable" when confronted with demanding tasks (medical record, August 9, 2007). When Trudy became frustrated during her middle school years, she would often engage in a toned-down version of the temper tantrums she threw as a small child, becoming visibly distraught and stomping off to her room (Kirsten, interview, July 5, 2017; Waylon, interview, June 29, 2017). Even as a teenager, Trudy would "sometimes become argumentative with adults if she is frustrated with a task" (IEP, February 3, 2017). A current point of contention with Trudy is her desire to drive like her sister, Karly. Trudy expressed her thoughts on not being able to drive during our interview:

I wanna say somethings that my sister does that I would love to do and I can't do because . . . It's called drive. And sometimes I get irritated cause she goes to her friends' house and I can't get out of the house or go anywhere, so I get really upset, but I'm mostly keeping it inside, inside the room. Inside the room, but now it's outside cause it's on a recording. (Trudy, interview, July 7, 2017)

When Trudy refers to "keeping it inside the room," she means keeping her emotions in check, keeping her frustration to herself and trying not to discuss how frustrated she is with her inability to drive. Like many people, Trudy has not only expressed her frustration through anger, but also through tears. However, Trudy's tears were not always an appropriate response as her mother explained:

I mean sometimes its appropriate stuff for kids to cry about, but sometimes it's not. You know like the kinds of stuff that she would get emotional and cry about, I mean I don't think that most kids would. Umm, and I don't know if maybe that's sometimes because she don't fully understand, you know, umm, stuff, I mean but she definitely, I mean those kind of things, just her anger and umm, and her you know emotionally crying uncontrollably. (Kirsten, interview, July 5, 2017)

As a teenaged student, Trudy has been known to respond inappropriately to disagreements with adults or peers by “crying, yelling, or running out of the classroom” at times (IEP, February 3, 2017). At age nine, Trudy's doctor observed that rather than cry, Trudy would “give up easily when working on more challenging activities” (medical record, August 9, 2007). Karly, Trudy's younger sister, talked about the fact that Trudy has faced many challenges throughout her life because of her injuries and said that in the past, Trudy “just, I mean she's gone into a default that when she can't figure out something the first time, she just doesn't want to do it anymore, she wants to give up” (Karly, interview, June 28, 2017). Together with neurological, cognitive and behavioral challenges, Trudy also faces academic challenges due to the brain injury she incurred as an infant.

**Academic challenges.** Since Trudy became school-aged, she has faced many academic challenges including reading, spelling, handwriting and math. As early as 36 months of age, Trudy was already exhibiting delays in academic readiness, as she achieved an approximate age level of 24 months (IEP, November 20, 2000). At seven years old, Trudy's IEP included goals for reading readiness and math skills, by setting the bar at 66% for mastery of short-term objectives in both areas (IEP, November 4, 2004). Trudy's mother discussed Trudy's difficulty with reading around this age:

I mean she could read like basic words, umm like “it, is, the,” you know those kinda words, probably in, probably when she was about, maybe when she was about 7 or 8. Umm, and she kinda stayed there for a few years, she didn’t really progress very much in reading. (Kirsten, interview, July 5, 2017)

When Trudy was nine years old, she was diagnosed as having a Learning Disorder Not Otherwise Specified, as her academic readiness skills were below average for her age and it was determined that she possessed “mildly to moderately impaired range abilities for her grade level” (medical record, August 9, 2007). During Trudy’s seventh grade year, she was able to read material written on a first-grade level, though she could not always comprehend what she read and she had difficulty decoding unfamiliar words (IEP, March 25, 2010). At that point, Trudy also had trouble writing simple sentences or paragraphs, in addition to having difficulty spelling. Trudy’s mother discussed her challenges with spelling during middle school:

I don’t know if its spelling as much as it’s like, you know, sounding the words out. Umm, I remember her middle school teacher, ‘cause I would be like why is she teaching her to spell stuff wrong? And then finally I asked her, I was like [Trudy] is like spelling stuff weird and I remember her telling me, “I don’t care how she spells it.” You know, she said “if that’s how it sounds to her, it’s more important that she can sound it out right than spell it right.” She said, “if that’s how it sounds to her, she knows what it is.” (Kirsten, interview, July 5, 2017)

Reading and spelling were not the only two areas where Trudy faced academic challenges in the seventh grade; math was challenging for Trudy, as well. Trudy struggled with grasping new math concepts, identifying coins and their values, telling time, and using a calendar appropriately (IEP, March 25, 2010). That same year, Trudy’s teacher remarked that though her “handwriting

[was] legible, Trudy did not always write on the lines of the paper” (IEP, March 25, 2010).

Trudy’s step-father, Waylon also commented that Trudy has had a “hard time with handwriting” over the years (interview, June 29, 2017).

***Current academic challenges.*** Throughout high school, Trudy continued to face academic challenges with reading, math and spelling. Waylon, Trudy’s step-father discussed Trudy’s continued challenges with reading, stating that Trudy “obviously doesn’t learn at the same capacity as other kids. So, like reading she has a hard time, making out words, or pronouncing words ‘cause she can’t read ‘em. I mean she can read, she just reads really slow” (interview, June 29, 2017). Trudy currently reads on a third-grade reading level and sometimes struggles with “retelling events” from stories she reads or with “comprehending reading passages on her level” (Ms. Smith, interview, May 22, 2017). Though Trudy’s spelling skills have improved, she still struggles with spelling words from time to time, as explained by her mother:

I mean she can sometimes sound out words that are spelled right, but she can’t always spell them back because it may not, you know, sound right. You know how K sounds like a C or C sounds like a K, so she may spell it with a C instead of a K, you know that kind of thing. Umm and she’s always struggled with that. (Kirsten, interview, July 5, 2017)

Trudy also continues to face challenges with math, specifically “adding mixed amounts of money” and identifying coins and their values, with the latter most likely due to her vision impairment more than her academic ability (Ms. Smith, interview, May 22, 2017). These academic challenges will continue to plague Trudy’s future and are a point of concern for her and her family members. Besides neurological, cognitive, behavioral and academic challenges,

Trudy has also faces social challenges due to the injuries she suffered as a survivor of an abusive head trauma.

**Social challenges.** The social challenges that Trudy has faced and will face all revolve around concerns from Trudy and her family regarding change and independence. During my interview with Trudy's younger sister, Karly talked about the fact that Trudy has had to go through many changes throughout her life, from physical changes to changing schools to changing home environments and now changes to her daily routine, as Trudy is participating in a hospital internship this school year that requires her to be away from the comfort of her high school classroom (Karly, interview, June 28, 2017). Change is not something that Trudy is comfortable with, at all; simply put, Trudy "hates change" (Karly, interview, June 28, 2017). Trudy discussed her feelings regarding leaving the security of her school environment in her audio-visual journal:

It was hard for me this week to leave school and leave all of my friends and classmates that I've known since ninth grade year and umm, and I guess not being able to come back is gonna be tough. But I know I will meet all new friends where I'm heading and where God is leading me. Umm, but that's the plan. That's God's plan for me, so. (Trudy, audio-visual Journal, May 25, 2017)

I understood that this change was stressful for Trudy as I received her recorded audio-visual journal the following week, where she continued to emphasize how sad she was to be leaving her school and her friends behind (audio-visual journal, June 4, 2017). During my interview with her, I asked Trudy how she was feeling about leaving school and she expressed how she felt on her last day at school:

ok the last day was pretty rough, I was trying to hold it together. Umm, the whole time, I kept looking back at my friend like “help me” (with a scared look on her face and then laughter). I think the hardest part was with Ms. [Smith] ‘cause she tried to hold it together. I tried so bad to hold it together. I was like breathe, breathe, breathe. (Trudy, interview, July 7, 2017)

Trudy is not comfortable with change, though she realizes that some of the changes she has experienced in the past have led to positive things happening for her. Another large concern for Trudy, her family, and her teacher is Trudy’s independence and to what degree she will choose to exercise independence. In speaking with Trudy, her family members and her teacher, several smaller concerns arose under the umbrella of independence. One of those concerns is transportation.

***Transportation.*** Trudy, like many other adolescents is obsessed with the thought of driving. Unlike other teens, who eventually do earn the privilege of driving, due to the injuries Trudy incurred because of the abusive head trauma, “she’ll never be able to drive. And she’s, I don’t know, she’s having trouble with that, the fact that’s she’s never gonna be able to drive” (Karly, interview, June 28, 2017). Both of Trudy’s parents work full-time and because Trudy cannot drive and her younger sister, Karly, who can drive, is enrolled in an online virtual school, Trudy currently relies on transportation on a bus for students in the special education program to get to and from her base school (IEP, February 3, 2017). In looking toward Trudy’s future, her mother provided a fuller picture of the concern with Trudy not being able to drive:

I think one of the biggest challenges, I would have to say, and I’ve brought this up to a lot of people, is transportation (laughter). I mean I do have to say that looking at, even thinking about her moving out and how she’s gonna, you know, get to work or get to the

grocery store to get, whatever she's got to do if I'm not, you know, right there or if I'm at work, you know, there's just not a lot of transportation options. Umm, umm and I think just everyday life stuff like going to the store. (Kirsten, interview, July 7, 2017)

***Independent living.*** Another concern regarding Trudy's independence is where Trudy will choose to live once she completes her internship at the local hospital and receives her Occupational Diploma from her high school. When Trudy was in seventh grade, a post-secondary goal established for her by her IEP team was that "she will live in a supportive residence in an area close to her family" (IEP, August 16, 2010). The idea that Trudy could live away from home and her perceived reaction to the notion of doing so was raised in several of the interviews with Trudy's family members, as well as her teacher (Jay, interview, June 17, 2017; Karly, interview, June 28, 2017; Keith, interview, June 16, 2017; Kirsten, interview, July 5, 2017; Ms. Smith, May 22, 2017; Waylon, interview, June 29, 2017). When researching post-secondary options for Trudy, her parents learned about the LIFE program offered by two colleges in Trudy's home state and decided to take Trudy to visit. Her step-father Waylon explained Trudy's reaction to the visit and the idea that she would live away from him and her mother:

Umm, of course, we, you know, visited CCU and talked with that lady and I think she's terrified of, you know kind of living out on her own or any kind of assisted living away from us, so... anything like that kinda scares her, so. (Waylon, June 29, 2017)

When I asked Trudy directly her thoughts on moving out of her parents' home and possibly living in a supportive residence, she responded emphatically:

No, definitely not! I don't have nowhere to go, so (laughter). It's like my heart's just not in it. Like moving away from home, I never really pictured that. Uhh, uh, naw, nope, as long as I pay the bills, that's all that matters. (Trudy, interview, July 7, 2017)

Trudy seems adamant that she does not want to move away from her family, even though her internship program at the local hospital is going to be encouraging her to be more independent. Trudy's teacher, Ms. Smith provided some insight into Trudy's hesitance regarding independence:

If she does live on her own, I believe she will be afraid and resistant at first because she loves living with her family. I believe that the challenges she will face will be learning many independent living skills. I believe that she has the potential to learn many of the skills and master them, but I think she will struggle to learn them and will have several frustrating moments. (Ms. Smith, interview, May 22, 2017)

Moving away from her family would be a huge change for Trudy, and as I have already explained, Trudy tends to reject change and feel uncomfortable when placed in situations that require significant change for her, at least until she adjusts to the new normal. Trudy's mother provided another example of the concern she and her husband have about Trudy's independence:

I feel like now, we do let her have a little bit of money now, you know we usually give her \$20 every couple of weeks and you know, I let her, when we go out to eat, I make her pay for her own dinner, you know. Umm, but sometimes she don't know, like she's supposed to wait for her change, you know, because she don't really know how much money she's givin' 'em. Umm, so we have to re- say, "hey make sure you get your change and a receipt." (Kirsten, interview, July 5, 2017)



These concerns are troublesome for Trudy and her family and are in heavy rotation during nightly dinner conversations (field notes, May 26, 2017; field notes, June 28, 2017). Though Trudy can stay at home unsupervised for short periods of time sometimes, her grandparents live right across the street, so they are readily available if Trudy should need them. Trudy's grandfather expressed that though Trudy has begun to take on some independence, learning to operate a microwave to cook, and staying alone for brief stretches of time, like many of her family members, he believes that Trudy is "always gonna have to have some form of supervision and some form of transportation" (Jay, interview, June 17, 2017). While Trudy's life as a survivor of an abusive head trauma has been wrought with neurological, cognitive, behavioral, academic and social challenges, she has employed several resilience mechanisms to cope with all of these challenges throughout her life.

### **Sub-Question 2: Resilience Mechanisms**

What resilience mechanisms does an adolescent survivor employ to cope with living with an abusive head trauma? (RQ2). Trudy has been on a strict medicine regimen since her injuries occurred at five months of age. On a daily basis, she currently takes two different medications for ADHD, one in the morning and one at night, two different medications to help control her seizures, one in the morning and one at night, two medications for encopresis, one allergy medication and one medication to stop menstruation since this would create an unnecessary challenge for her. In addition to her medicine regimen, which helps her cope with some of the challenges that she has faced, Trudy has participated in occupational, physical, and speech-language therapies to varying degrees throughout her life. Though she no longer participates in speech-language therapy or physical therapy, she does continue to participate in occupational therapy through her high school. To cope with the many challenges that Trudy has faced

throughout her life, she has received medical, as well as therapeutic assistance, but equally important are the resilience mechanisms that Trudy employs to cope with life as a survivor of an abusive head trauma. These resilience mechanisms include: (a) a large support network, (b) adaptive behavior, (c) faith, and (d) perseverance.

**Large support network.** The most common theme regarding Trudy's resilience across all of the interviews and observations conducted is the presence of a large support network in Trudy's life. After Trudy was released from the hospital following the injuries she incurred due to the abusive head trauma, her mother, Kirsten "did everything the doctors said to do, you know. If it was to do exercises, we did exercises with her, you know. Anything they said to do, to try, [Kirsten] tried" (Christy, interview, July 1, 2017). One thing was clear early on, that Kirsten wanted to equip Trudy to be the best version of herself that she could be. Trudy's mother believes in her and her ability to live a productive life, as she explained:

I do try and have always tried to push her to, you know, I don't want to say be normal, that's probably not the right word, but do normal stuff, you know, like to do what normal kids do. You know like you have chores, well normal kids have chores, you know. You have to clean your room, normal kids have to clean their rooms, you know, you need to help sweep the floor. You know and just not try to lim...I, I really tried not to limit her on what she can do because of her disability. I tried to push her to, no, you might not do it perfect and that's ok, you don't have to be perfect, but you know, but you need to try to do these things because that's just how, you know, life is, you know, you have to at least try to do these things. Umm, so I've just kind of always pushed her to do those, you know, everyday life things, so. (Kirsten, interview, July 7, 2017)

Trudy's mother and her step-father, Waylon, both have a very positive outlook on life and they have attributed greatly to Trudy's optimistic attitude by encouraging her to do her best to the best of her potential (Christy, interview, July 1, 2017; Jay, interview, June 17, 2017). Trudy's step-grandmother explained that Trudy "mostly is just conditioned to be positive because her parents are. Her family has expected that of her" (Sue, interview, June 17, 2017). Trudy is held accountable by many different pieces of her support network and she is not allowed to pity herself. Trudy's support network extends beyond just her family, to "everybody from neighbors to grandparents to people on the ball team to everybody, church, she has such a huge network that know and love her and understand her" (Sue, interview, June 17, 2017). A large part of Trudy's support network, outside of her family, has been school, where she has received special education services throughout her academic career. Trudy's teacher agreed that Trudy's family has been essential to her development of resilience:

Most of my students will probably not go on to have a job after high school or go to more schooling, but [Trudy] is an exception. She has an amazing family that supports her and wants to see her succeed and become more independent. (Ms. Smith, interview, May 22, 2017)

As far as her own feelings regarding the nature of her support network, Trudy understands that she is "loved and that [she has] lots of help from family, friends, and teachers and people at her church" (Trudy, interview, July 10, 2017). In addition to this large support network, Trudy has developed resilience through adaptive behaviors, which allow her to cope with the challenges that she has faced.

**Adaptive behaviors.** Besides wearing prescription eyeglasses to cope with her vision impairment, Trudy has been provided with assistive technologies in her academic environment,

such as various magnifiers to use at her desk and large, flat-screen computer monitors with settings adjusted to magnify all onscreen content, as well as having access to large printed materials and large graphics (IEP, February 3, 2017). Since Trudy sees through only a tiny pinhole view, she has a tendency to “cock her head or, or move her eyes back and forth so she can find, or to line the hole up to see through it” (Jay, interview, June 17, 2017). I also observed that Trudy holds her head very close to the screen of her cell phone and iPad and turns her head to the left to better focus when she is attempting to read something on these digital devices and when she is watching television, she sits very close to the screen (field notes, May 27, 2017; field notes, June 16, 2017). Along with these adaptive behaviors to address her vision challenges, Trudy has been known to mimic the behaviors of her peers in the past:

When [Trudy] was going to the Merry Center, it was a little school for well all kind of special needs, she befriended a child there that didn't have arms. Well, [Trudy] was still just learning, she might have been sitting up by now, but she wasn't really walking just yet, well she was walking, but not very good and she kept trying to eat with her feet (laughter). Come to find out, she was learning it from her friend at school that didn't have arms, who ate with her feet. She used her utensils with her toes. (laughter) (Jay, interview, June 17, 2017)

Though Trudy had no physical reason for engaging in this particular adaptation, she was modeling the behavior of her peers to overcome a perceived challenge. Once Trudy reached middle school age, her teacher taught her some exercises to combat her behavioral challenges, specifically ways to calm herself:

Her teacher would tell [Trudy] to, you know, go to your room and you know, kinda set there until you calm yourself down. Go for a walk and you know, she does that, you

know, when she gets really upset or me and her get in a heated argument or you know whatever, she'll just go take a little walk around the circle and she'll come back and she'll say, "I'm better now." (Kirsten, interview, July 7, 2017)

Trudy continues to use these calming coping strategies when she becomes frustrated. Trudy's parents also model these strategies for her, so that she will understand that taking a break or a time out to cool off is a more appropriate way to deal with frustration than to let frustration get the best of her (Kirsten, interview, July 7, 2017; Waylon, interview, June 29, 2017). Because of the coping skills she has developed, when Trudy has difficulty understanding things or when she has a problem, "she wants to talk through it; she wants to understand it and why it's happening and resolve it" (Vicki, interview, June 24, 2017). To address some of the organizational challenges that Trudy faces, her parents encourage her to make lists "or we'll just give her a couple of things and she knows now, she's like 'I gotta go do it right now' or we give her things to do that have just a few steps" (Kirsten, interview, July 7, 2017). Trudy can accomplish large tasks if those tasks are broken down into smaller parts (IEP, February 3, 2017). Coupled with a large support network and adaptive behaviors, Trudy's resilience is based on her faith.

**Faith.** Trudy and her family are very involved in the church that they attend. Trudy's parents both volunteer with children's programs and Trudy's younger sister, Karly is a teen group leader at the church. Karly is also heading to California after graduation from high school in the spring to live and work at a missions' center that serves underprivileged youth and adults. Trudy, along with her sister, has attended a summer camp for youth, sponsored by her church, every year for the past several years. Trudy's youth group leader, Vicki, works with students with special needs at the church and she accompanies Trudy and other students with special needs on these trips to summer camp. Trudy recently started volunteering in the pre-school

classroom at her church, working with three and four-year old children, which she enjoys and “feels like [she] is getting more work experience because she is surrounded by people [she] know[s]” (Trudy, interview, July 10, 2017). Because Trudy and her family are so involved in church, it was no surprise that Trudy attributes her resilience to her faith in God. When I asked Trudy how she handles difficult situations, she responded:

Most of the time, I do get mad but then I’m like (looking upwards) “alright, what do I do, tell me?” When I don’t know, I just go in my room and I’m like “[Jesus] tell me what I need to do” and then He tells me so I leave my spot and then I come in here, then I go back to it, and sooner or later I’ll figure out how to do it. (Trudy, July 10, 2017)

Trudy believes that she has a purpose in life because of her belief in God. She talked about her reliance on God and her love for her church all throughout her interview, as well as in her audio-visual journal. At the end of our interview, I asked Trudy if she could only tell people one thing about herself, what would it be and she said “umm, that I was a gift from God and that God blessed me to let me live and that umm, Jesus was right there with me the whole time” (Trudy, interview, July10, 2017). Along with attributing Trudy’s development of resilience to a large support network, adaptive behaviors, and faith, Trudy’s resilience is strengthened through perseverance.

**Perseverance.** Trudy has not always been one to persevere. Perseverance is a skill that has been modeled and taught to her by her parents and others around her over time. Trudy’s mother, Kirsten recounts how she began to instill a sense of perseverance in Trudy:

For a long time, I told her that “can’t” was a bad word (brief laughter), umm, because I hate for her to say that. For me, as a mom, I want her to know that there may be stuff that you can’t do that’s right, but you just need to try, you know. I mean we usually try to

encourage her to, you know, try to her ability to be able to do it. (Kirsten, interview, July 7, 2017)

Trudy's younger sister, Karly corroborated her mother's story about teaching Trudy to persevere and talked about the fact that they encourage Trudy to "just keep trying because, I mean we all have things that we don't think we can do, umm, but she just keeps trying and she keeps working at it and overcomes it" (Karly, interview, June 28, 2017). Because she has learned to persevere, Trudy "is self-motivated in her school work and takes pride in her accomplishments" (Ms. Smith, interview, May 22, 2017). Trudy shared an example of her perseverance during our interview:

Uhh, well I did it with math, so I want to go back in time. When I started counting money, that was really difficult for me. Like I would get really frustrated. Like I would try it and put a 20 with another one and it wouldn't be right and the teacher would say that's not right. Before too long, I got up with it and now she's started putting 10s and 20s and 30s in the thing and I finally got to where I can count them. (Trudy, interview, July 10, 2017)

Clearly, Trudy has developed a strong sense of perseverance that has contributed to the resilience mechanisms that she employs to cope with living as a survivor of an abusive head trauma. Trudy has also begun to advocate for herself when she feels frustrated or overwhelmed (Kirsten, interview, July 7, 2017; Ms. Smith, interview, May 22, 2017). Along with the challenges that Trudy has faced throughout her life, as well as the resilience mechanisms that she has developed to cope with living with these challenges, it is important to gain insight into Trudy's experience as an adolescent survivor of an abusive head trauma to inquire about the advice that she would give to another adolescent who has experienced a similar trauma.

### **Sub-Question 3: Advice**

What advice would an adolescent survivor give to someone who has experienced an abusive head trauma? (RQ3). Trudy is a people person and she desires, more than anything else, to help people. When I asked her to tell me what advice she would give to someone who had experienced the same type of injury that she has experienced, she was more than happy to oblige:

If someone had my disability, I would just explain the situation. It's ok to have the same disability, because I have the same thing too and I'm dealing with the same thing you're dealing with and we can go through this together. And whatever you're going through, I'm definitely going through it. You just have to believe that you can do it. (Trudy, interview, July 10, 2017)

Trudy was recently featured on her local news and interviewed about her participation in Project SEARCH. Trudy discussed one of her accomplishments since she has been in the program, which involves wrapping the chords of medical equipment that she cleans; "It's my favorite part because I had a hard time doing it and I accomplished it" (Trudy, interview, September 27, 2017). Trudy is a living example that developing resilience has helped her to accomplish things that once were difficult. It is interesting to see that Trudy chose to say, "it's ok" to have a disability and also that she mentioned "we can go through this together" in the advice that she provided (Trudy, interview, July 10, 2017). Her optimism and desire to help others is strong and has most definitely shaped her experiences as a survivor of an abusive head trauma.

### **Summary**

Chapter Four includes a discussion of the participants involved in this narrative life history of an adolescent survivor of an abusive head trauma. Since the study focused on the life history of the primary participant, the participant discussion begins with a brief introduction to



the secondary participants involved, followed by a thick, rich description of Trudy, the primary participant's life history. Following Trudy's life history, is the results section, which begins with a discussion of theme development, followed by a thick, rich responses to the three research sub-questions guiding this study. The results of this study revealed that challenges faced by Trudy, the primary participant, included: (a) neurological, (b) cognitive, (c) behavioral, (d) academic, and (e) social. While Trudy utilized (a) a large support network, (b) adaptive behaviors, (c) faith, and (d) perseverance as resilience mechanisms to cope with living with an abusive head trauma. To conclude, Trudy's advice to adolescent survivors of trauma like the type she incurred was that living with a disability is doable and to seek a support network.

## **CHAPTER FIVE: CONCLUSION**

### **Overview**

The purpose of this narrative study was to describe the life history of an adolescent survivor of an abusive head trauma in the Southeastern United States. Chapter Five includes a summary of the findings of the study, before moving into a discussion of the findings and implications of the study in light of the relevant literature and theory. Next, is a discussion of the methodological and practical implications of the study, along with an outline of the study delimitations and limitations. Recommendations for future research are presented before the chapter concludes with a succinct summary of the study.

### **Summary of Findings**

The central question guiding this research study was “What are the lived experiences of an adolescent survivor of an abusive head trauma in the Southeastern United States?” To fully develop a thick, rich description of Trudy, the primary participant’s life history, three sub-questions were developed and explored. First, “what challenges does an adolescent survivor of an abusive head trauma face?” (RQ1). The findings of this study revealed that Trudy has faced (a) neurological, (b) cognitive, (c) behavioral, (d) academic, and (e) social challenges throughout her life as a survivor. Her neurological challenges include seizures, vision impairment as a result of retinal detachment, impaired walking and delayed fine and gross motor development. Cognitively, Trudy’s challenges have included impairments in language and executive functioning, specifically impaired reasoning, organization, attention, and memory. Behaviorally, Trudy has experienced extreme bouts of anger, frustration, temper tantrums, crying, and feelings of defeat. Trudy’s academic challenges have manifested in reading, as she can read only on a third-grade level, inability to spell words correctly, impaired handwriting and low-level math

skills. While Trudy's social challenges focus on coping with changes in routine and life in general, as well as concerns regarding future transportation issues and independent living.

Secondly, "what resilience mechanisms does an adolescent survivor employ to cope with living with an abusive head trauma?" (RQ2). Results of this study revealed that Trudy employed four resilience mechanisms to cope with life as a survivor: (a) a large support network, (b) adaptive behaviors, (c) faith, and (d) perseverance. Trudy's large network includes her family members, friends, church, school, baseball team, and neighbors, all of whom work together to provide support for her as she navigates the challenges of living with an abusive head trauma. Regarding adaptive behaviors, Trudy utilizes assistive technologies to cope with her vision impairment, as well as compensating for her poor vision by turning her head in a certain direction to see better, or sitting close to a television screen or monitor. Trudy has also mimicked the behavior of peers as a way to navigate challenges and as she has grown, she has learned calming strategies and that talking through problems helps her to better understand the challenges that she faces. Trudy is a Christian and relies heavily on her faith in God to help her persist in challenges and she has cultivated a sense of perseverance that allows her to work through challenging situations.

Finally, "what advice would an adolescent survivor give to someone who experienced an abusive head trauma?" (RQ3). Trudy's advice to someone who experienced a similar form of trauma to the one she has endured firstly, emphasized that having a disability is "ok" (Trudy, interview, July 10, 2017). Secondly, Trudy also reaffirmed her belief in the importance of having a strong support network to cope with facing challenges that lie ahead.

## Discussion

Many quantitative studies have been conducted regarding various aspects of an abusive head trauma, including risk factors, signs and symptoms, outcomes, and prevention and intervention strategies. Until now, no qualitative studies have focused on the experience of an adolescent survivor of an abusive head trauma. In the following sections, I will discuss the findings of the current study in light of the empirical and theoretical literature, including ways in which the current study confirms or diverges from previous research, introduce novel contributions adding to the field, and how the study extends the theories informing the topic.

### Findings Related to Empirical Literature

In this section, I begin the discussion of the findings in light of the empirical literature presented in Chapter Two of this current study. This discussion begins with an examination of Trudy's cognitive and psychosocial development compared to the literature on adolescent development by Piaget (1936/1953), Erikson (1959/1980) and Bruner (1966), followed by a discussion of multiple dimensions of identity and how that applies to how Trudy views her own identity. After which, I discuss Trudy's life history in relation to the risk factors, signs and symptoms, outcomes and prevention and intervention programs and strategies presented in Chapter Two. Lastly, I compare Trudy's life history to the available qualitative literature on adolescents with a traumatic brain injury included in Chapter Two of this study.

**Adolescent development.** Jean Piaget (1936/1953) argued that individuals progress through four stages of cognitive development, through which they construct schema to build their knowledge of the world upon, as they move from infancy through adulthood. A regular arc of cognitive development within this structure would result in an individual progressing from the sensorimotor stage to the pre-operational stage, then to the concrete operational stage, before

finishing in the formal operational stage as an adult. Whereas Piaget (1936/1953) emphasized a chronological progression through the stages of cognitive development, Bruner (1966) propagated three modes of representation of knowledge that are integrated as an individual develops cognitively. In Bruner's (1966) cognitive development theory, one may represent knowledge through enactive representation (actions stored as muscle memory), iconic representation (stored as images or mental pictures), or symbolic representation (expressed as words and symbols). As a result of the abusive head trauma she suffered, Trudy's brain injury caused significant delays in her cognitive development and inhibited her ability to progress through each of Piaget's (1936/1953) stages. Based on the data collected, Trudy's cognitive development places her in Piaget's (1936/1953) concrete operational (which generally occurs between ages 7-11) stage, as she has faced challenges regarding reasoning, organization and memory. In regard to Bruner's (1966) modes of representation, Trudy exhibits knowledge through enactive representation, iconic representation, and to a small degree, symbolic representation. While Piaget's (1936/1953) and Bruner's (1966) theories addressed cognitive development, Erikson (1959/1980) addressed psychosocial development. Erikson asserted that an individual's personality is influenced by culture and society and the positive or negative resolution of psychosocial crises that occur across one's lifespan. Because Trudy's injury occurred when she was only five months old, she experienced negative resolution of the trust v. mistrust crisis, which has resulted in her experiencing anxiety and insecurity when faced with change or new situations. Regarding the autonomy v. shame and doubt crisis, Trudy experienced somewhat of a negative resolution, as well, which at times has resulted in her being overly dependent on others, however, she does not seem to experience low-self-esteem, as suggested by Erikson's (1959/1980) theory. With the initiative v. guilt crisis, Trudy experienced a positive

resolution and takes initiative in her approach to school work and house work, however, she sometimes displays insecurity in her ability to make decisions. Trudy has also had positive resolution to the industry v. inferiority crisis, as she exhibits high self-esteem and pride in her ability to perform certain tasks, such as reading to her classmates and playing baseball, or competing in the Special Olympics. Finally, regarding the identity v. role confusion crisis, Trudy has definitely experienced positive resolution, as she has developed a healthy identity and a strong sense of loyalty to others. Along with gaining insight into Trudy's cognitive and psychosocial development, it is important to examine the multiple dimensions of how she identifies herself, as well as how others identify her.

**Multiple Dimensions of Identity.** All individuals develop multiple dimensions of identity, specifically: (a) individual identity, which is a core sense of self, excluding external attributes, and (b) social identity, which is who we are to others, often associated with external descriptors or labels (Abes, Jones & McEwan, 2007). Trudy has clearly developed a healthy individual identity, as she describes herself as “a child of God and a Christian, caring, funny and I make everybody smile and laugh” (Trudy, interview, July 10, 2017). In our discussions and my observations of her, Trudy never mentioned her physical appearance or any other external attributes. As far as social identity, Trudy conveys a positive sense of self to others, so that when secondary participants were asked to describe her, each of them reiterated how Trudy sees herself, as funny, sweet, caring, kind, smart, and not one person mentioned external descriptors. Trudy's social identity correlates with her individual identity, which is exactly how Trudy wants to be viewed. In addition to understanding Trudy's cognitive and psychosocial development, as well as how she and others view her identity, it is essential to examine Trudy's life history in light of the risk factors that exposed her to the abusive head trauma that she endured as an infant.

**Risk factors for abusive head trauma.** One of the most pervasive factors in cases involving abusive head trauma is inconsolable crying by an infant or child, coupled with a lack of caregiver knowledge about how to manage this behavior (Barr, 2012; Chevignard & Lind, 2014, Díaz-Olavarrieta et al., 2011; Mok et al., 2010; Parrish et al., 2013; Stoll & Anderson, 2013; Tanoue & Matsui, 2015; Xiang et al., 2013). Another prominent factor in cases involving abusive head trauma is that the perpetrator is most often a male, who may or may not be related to the child, but who is living in the child's home (Adamsbaum et al., 2010; Barr, 2012; Bechtel et al., 2011; Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Parrish et al., 2013; Postema et al., 2014; Stoll & Anderson, 2013). While additional factors that increase the risk of abusive head trauma for children include low parental socioeconomic status, unintended pregnancy, parental alcoholism, young age of the infant, young ( $\leq 20$ ) and unwed mothers with less than 12 years of education, and the presence of domestic violence (Adamsbaum et al., 2010; Bechtel et al., 2011; Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Parrish et al., 2013; Postema et al., 2014; Stoll & Anderson, 2013, Tanoue & Matsui, 2015; Xiang et al., 2013). Unfortunately, many of these factors figured prominently into Trudy ultimately suffering an abusive head trauma at the hands of her teen-aged biological father when she was just five months old. Trudy's parents were both teenagers when Trudy was born, so neither of them had completed high school yet and though they were unmarried, they lived together at Trudy's father's parents' home. Trudy's mother, Kirsten, indicated that there had been some incidences of domestic violence against her by Trudy's biological father prior to Trudy being abused (Kirsten, interview, July 5, 2017). In his confession, Trudy's biological father stated that "Trudy would not stop crying and that is why he choked her and threw her down on the ground" (Kirsten, interview, July 5, 2017). The risk

factors for abusive head trauma, were unfortunately confirmed by Trudy's life history. Next, I discuss the signs and symptoms of an abusive head trauma and how they applied to Trudy's case.

**Signs and symptoms of an abusive head trauma.** One of the most prevalent signs that an infant or child has suffered an abusive head trauma is often the presence of a subdural hematoma, or significant bruising of the brain (Adamsbaum et al., 2010; Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Postema et al., 2014; Stoll & Anderson, 2013). However, the presence of a subdural hematoma alone may not be enough to diagnose a child as having suffered an abusive head trauma. Medical examiners need to exercise caution in cases of suspected abuse and therefore, in addition to a subdural hematoma, other factors must be present before making a diagnosis including the presence of one or more of the following: coma, seizures, retinal hemorrhages, cranial fracture, cerebral edema (accumulation of fluid in the brain) and atrophy, cervical injury, bruising in various stages of healing, and other fractures in various stages of healing (Adamsbaum et al., 2010; Barr, 2012; Chevignard & Lind, 2014; Díaz-Olavarrieta et al., 2011; Kadom et al., 2014; Postema et al., 2014; Stoll & Anderson, 2013). Findings in this study revealed that Trudy's medical team determined that she had suffered an abusive head trauma after she presented with a subdural hematoma, along with having had a seizure, retinal hemorrhages and retinal detachment, a cranial fracture, bruises in various stages or healing and rib fractures in various stages of healing. Regrettably, Trudy's case confirmed the previous research concerning signs and symptoms of an abusive head trauma. Now that I have discussed how Trudy's case confirmed the risk factors and signs and symptoms of an abusive head trauma, I will examine her outcomes in light of the previous research.

**Outcomes.** In most cases of abusive head trauma, survivors face long-term neurological, cognitive and behavioral challenges that must be addressed through special education services as



the child progresses through school (Chevignard & Lind, 2014; Lind et al., 2016; Risen et al., 2014; Xiang et al., 2013). The findings of this study indicate that Trudy has faced neurological challenges, in the form of seizures and vision impairment, impaired walking and delayed fine and gross motor development; cognitive challenges with language and executive functioning, specifically in the areas of reasoning, organization, attention, and memory; behavioral challenges, which have manifested as anger, frustration, temper tantrums, crying, and feelings of defeat. In addition to these challenges mentioned in the previous research, Trudy has also experienced academic deficits in the areas of reading, spelling, handwriting, and math, as well as social challenges tied to change, transportation, and independence. All of these challenges have resulted in the need for Trudy to receive special education services, which she is entitled to under the designation of Traumatic Brain Injury as authorized by the federal IDEA (2004) mandate. The reauthorization of IDEA (2004) also mandates transition services for students receiving special education, so that students have access to school-to-work opportunities following high school, as well as post-secondary education options (U.S. Department of Education, 2010). Trudy is taking advantage of this part of the mandate, as she will be participating in a year-long internship through Project SEARCH, at a local hospital in the city where she lives. This internship will allow Trudy to receive training that could lead to viable employment for her upon completion of the requirements for her Occupational Diploma, awarded by the state in which she lives. Regarding long-term medical costs discussed in the previous research, Trudy's family could not even begin to estimate the monetary costs associated with Trudy's care as a survivor of an abusive head trauma (Kirsten, interview, July 5, 2017). She has been on a strict regimen of medications since suffering the abuse as a five-month-old infant, in addition to receiving occupational, physical and speech-language therapies at various points in her recovery, as well as

using assistive technologies to address her vision and organizational deficits. Trudy's family, like those mentioned in the previous research, will also help Trudy to ultimately decide how much independence she will have in regard to living with her parents or living in an assisted community setting, with both choices incurring high monetary expenses for Trudy's family. Alas, Trudy's case once again confirms the previous research on the outcomes for survivors of an abusive head trauma. Examining the outcomes for Trudy lead to a desire to explore the prevention and intervention programs and strategies that exists to address the risk factors associated with abusive head trauma.

**Prevention and intervention programs and strategies.** The literature revealed that though there are several effective prevention programs and intervention strategies available for use to address the risk factors for abusive head trauma (Bechtel et al., 2011; Simonnet et al., 2014; Stoll & Anderson, 2013), these programs and strategies are not always required, accessed or employed. In Trudy's case, her mother Kirsten received prevention education as a part of the teen parenting program that she was required to attend in order to remain in high school as an expectant mother. However, the same program, which was a requirement for teen mothers to complete to remain in school, was not required for Trudy's biological father, who was also a teenager and therefore, he did not receive any type of prevention or intervention training. Ultimately, his lack of education regarding strategies to deal with Trudy's inconsolable crying played a prominent role in his decision to harm her, hereby confirming the previous research. Finally, I discuss Trudy's life history in light of the previous qualitative research available regarding adolescents who have suffered a traumatic brain injury before moving into a discussion of the theoretical literature.

**Qualitative literature on adolescents with traumatic brain injuries.** Though the literature was thin regarding qualitative studies focused on adolescents who have suffered a traumatic brain injury, three such studies focus on the experiences and include the perspectives of these young people (Gauvin-Lepage & Lefebvre, 2010; Iadevaia, Roiger, & Zwart, 2015; Mealings & Douglas, 2010). Two major differences arose regarding these three studies and Trudy's life history, which were that all of these injuries were accidental and incurred in adolescence and all of these adolescents were expected to make a full recovery from their injuries (Gauvin-Lepage & Lefebvre, 2010; Iadevaia, Roiger, & Zwart, 2015; Mealings & Douglas, 2010), while Trudy's injury was inflicted on her as a five month old infant by her biological father and she will not make a full recovery at any time from the injuries that she incurred. One similarity between the cases presented in the previous research and Trudy's case was that most of the adolescent survivors and their family members indicated that their family bonds had strengthened as a result of their injuries (Gauvin-Lepage & Lefebvre, 2010; Iadevaia et al., 2015; Mealings & Douglas, 2010), as was the case for Trudy and her family (Jay, interview, June 17, 2017; Kirsten, interview, July 5, 2017). Now that I have discussed Trudy's life history in light of the empirical research, I will turn my discussion towards how Trudy's life history relates to the theoretical literature that informed this study.

### **Findings Related to Theoretical Literature**

Not only is it essential to examine Trudy's life history in light of the empirical literature, but it is equally important to ground this narrative study in theory. Three theories formed the framework for the current study: (a) Bronfenbrenner's (1979) ecology of human development, as it focuses on the relationship between individuals and their environments, (b) Ungar's (2012) theory of social-ecological resilience, as it explores the relationship of individual's resilience and

their environments, and (c) Bandura's (1986) social cognitive theory, as it emphasizes the importance of self-efficacy's relationship to resilience. Trudy's life history will be examined in light of these three theories in the discussion that follows.

**Bronfenbrenner's (1979) ecology of human development.** Bronfenbrenner (1979) posited that an individual's environment is divided into a system of five levels: the microsystem, the mesosystem, the exosystem, the mesosystem, and the chronosystem. Whereas, the microsystem is an individual's direct environment (e.g., family, home, school), the mesosystem is the relationship between microsystems. While the exosystem links the context in which individuals are not active participants to contexts in which individuals are active participants, the macrosystem consists of one's culture and the chronosystem is made up of transitions and shifts experienced by individuals across the lifespan. Understanding these various systems helps to clarify the role that demographic risk factors played in Trudy's injury, such as the macrosystem, which required her mother to receive prevention education, but not her biological father. This theory also aids in understanding the formation of resilience mechanisms that Trudy has developed, such as a large support network, made up of the various microsystems (e.g., family, home, school, church, baseball team) of which she is a part and how those microsystems interact in the mesosystem to support her. This mention of resilience leads into an examination of Trudy's life history in light of Ungar's (2012) theory of social-ecological resilience.

**Ungar's (2012) theory of social-ecological resilience.** Based on Bronfenbrenner's (1979) ecology of human development, Ungar's (2012) theory of social-ecological resilience emphasized that an individual's resilience should be studied through one's interactions within various environments. In order to understand how Trudy developed resilience mechanisms, it was important to study her individual traits in terms of the environments in which she interacts,

such as home, school, church and her baseball team. Ungar's (2012) theory proposed that development of resilience is based on three principles: (a) equifinality (many good means to many good ends), (b) differential impact (different protective processes influence resilience differently depending on the individual's exposure to risk), and (c) contextual and cultural moderation (protective processes are valued and made available differently in different contexts and cultures). Regarding equifinality, Trudy is encouraged by her large support network to complete tasks to the best of her ability, resulting in Trudy persevering to complete the task at hand, which creates feelings of accomplishment and pride in Trudy. With differential impact, Trudy has a large support system that encourages her to take healthy risks, especially where her independence is concerned and Trudy also relies on her faith to help guide her when she is unsure or insecure. Trudy's support network operates with contextual and cultural moderation to encourage perseverance in the face of adverse situations for Trudy. All of these supports have allowed Trudy to safely develop resilience mechanisms to cope with life as a survivor of an abusive trauma. Lastly, I will discuss Trudy's life history in light of Bandura's (1986) social cognitive theory.

**Bandura's (1986) social cognitive theory.** Bandura (1986) argued that learning happens through triadic reciprocal causation through interactions among personal characteristics, behavioral patterns, and social environment. This theory is based on five central concepts: modeling, outcome expectancies, self-efficacy, goal setting, and self-regulation (Bandura, 1986). Of these five concepts, self-efficacy aids most in understanding resilience in survivors of traumatic events, such as the abusive head trauma that Trudy endured. Interaction between social, cognitive, behavioral and psychological factors influence motivation and when positively correlated can create a strong sense of self-efficacy (Bandura, 1986). Throughout her life as a

survivor of an abusive head trauma, Trudy has been able to lean on a large network of people made up of family, friends, teachers, church members, baseball coaches and team mates, and neighbors to encourage her to persevere through difficult situations. She has also engaged in adaptive behaviors to cope with difficulty, and she relies heavily on her faith in God to lead her through tough circumstances. As a result, Trudy's self-efficacy has blossomed and she is better equipped to adapt to new environments and attain goals that she has for herself.

### **Implications**

On any given day, across the United States, children suffer at the hands of those who are meant to protect and care for them. Abusive head trauma is a serious form of abuse that results in fatalities for many children, while those who survive are affected by neurological, cognitive, behavioral, academic and social challenges for the remainder of their lives. In the following sections, I will address the theoretical, empirical, and practical implications of the findings of Trudy's life history.

#### **Theoretical Implications**

This narrative study explored the influence of environment on an adolescent survivor of an abusive head trauma, Trudy, and her developed resilience and feelings of self-efficacy (Bandura, 1986; Bronfenbrenner, 1979; Ungar, 2012). Until the current study, these theories had not been used to frame an inquiry into the development of resilience in an adolescent survivor of an abusive head trauma. This study of Trudy's life history clearly reveals that her environment played a role in both her abuse and in her development of self-efficacy and resilience mechanisms to cope with surviving an abusive head trauma.

### **Empirical Implications**

While the existing research on this topic has been overwhelmingly quantitative, there have been no qualitative research studies exploring the human experience of surviving an abusive head trauma until now. This narrative life history addresses the gap in the literature to make an original, empirical contribution as a qualitative study allowing an adolescent survivor of an abusive head trauma and those who care for her to share her lived experience, as no other qualitative studies on this topic exist. The current study also serves to confirm the previous quantitative research on risk factors, signs and symptoms, and outcomes for survivors of an abusive head trauma.

### **Practical Implications**

One practical implication of Trudy's life history is the importance of administering prevention and intervention programs and strategies to both parents and any other adults who will care for a child during the perinatal period, in the weeks leading up to birth or shortly following the birth of a child. A second practical implication of this study of Trudy's life history is the essential nature of forming a strong support network made up of medical team members, therapists, family members, friends, teachers, and other people important to a child's neurological, cognitive, behavioral, academic and social well-being, following an abusive head trauma. In Trudy's case, the medical care team who initially diagnosed and provided treatment for Trudy's injuries also provided Trudy's mother with a list of contacts including therapists, support groups and other community resources able to provide immediate support and assistance to Trudy and her family. Trudy's mother took the initiative to contact these resources so that Trudy could begin therapy right away to address the areas affected by her injuries. Trudy's mother and other family members received counseling to cope with what had happened to Trudy

and to understand the reality of the challenges that Trudy would face throughout her life. Trudy was enrolled in a pre-school for children with special needs in the area where she lived and the teachers, counselors and therapists at that school became part of her support network. Along with Trudy's family members, medical care team, teachers, counselors, and therapists, Trudy's church family became an extended part of her support system. Additionally, when Trudy entered middle school, she became involved in a baseball league for children with special needs and that groups of coaches, as well as her teammates became a part of her large support network. This large support network has been essential to Trudy's ability to cope with the challenges she has faced as a survivor of an abusive head trauma. A third implication is for a child's support network to encourage self-efficacy in a child who has suffered an abusive head trauma so that the child will come to believe that goals are attainable and will have a more positive outlook on new situations to which they are exposed and feel more secure in their own independence. This can be accomplished by encouraging the child to complete tasks independently to the best of their ability, breaking down larger tasks into small parts so that the whole task may be completed without becoming overwhelming. Praise is important during the building of self-efficacy, as a means to help the child grow more confident as tasks are completed with success.

### **Delimitations and Limitations**

Delimitations are characteristics within the control of the researcher utilized to limit the scope and define the boundaries of a qualitative study (Simon, 2011). The first delimitation of this study was the choice to focus on a narrative, life history of an adolescent survivor of an abusive head trauma. Related problems could have been chosen, but were eliminated in favor of the current study. Another delimitation of this study is the decision to limit participation to a primary participant who is at least 18 years of age. In light of the sensitive nature of this study's



focus on a survivor of child abuse, I chose to avoid including younger participants in the study to minimize retraumatizing the participant. Since this injury occurred at such a young age, Trudy has navigated her entire life as a survivor of an abusive head trauma. As such, she has coped with this trauma on a daily basis throughout her life. A third delimitation is the choice to study a single participant using a narrative, life history versus a single, instrumental case study design. Creswell (2013) advises that a narrative approach is more appropriate as “narrative studies tend to focus on a single individual whereas case studies often involve more than one case” (p. 102) and the purpose of this study was to gain a deep understanding of Trudy’s lived experiences as a survivor of an abusive head trauma rather than to make a broad generalization about surviving an abusive head trauma.

Whereas delimitations are within the researcher’s control, limitations are outside of the researcher’s control and appear as potential weaknesses in the study (Simon, 2011). The limitations of the current study are that the narrative design may inhibit transferability, as a single individual’s experience with an abusive head trauma is being reported. Another limitation is that the geographical location of the study, in the Southeastern United States, may also prevent generalization to other populations of survivors of an abusive head trauma in other geographic locations. A third limitation is time. Though this study reports a life history of the participant, I acknowledge that the participant’s age provides for a time span of 19 years. Therefore, the study may not be applicable to older populations of survivors of an abusive head trauma. A fourth limitation is that the research is retrospective versus prospective as the study is looking backward to examine the lived experiences of a survivor of an abusive head trauma.

### **Recommendations for Future Research**

In consideration of the study findings, limitations, and the delimitations placed on the study, I would make several recommendations for future studies related to the current study. One recommendation would be to study a mother's experience with raising a child who has been subjected to and survived an abusive head trauma. This study could be carried out as a narrative life history, or as a phenomenology if several participants could be identified and indicated a willingness to participate. A second recommendation would be to study a step-father's experience with parenting a child who has suffered an abusive head trauma at the hands of a biological father. Again, this study could be conducted as a narrative history or as a phenomenology, depending on the number of participants involved. A third recommendation would be to conduct a study of the non-abused siblings who have grown up with a sibling who has suffered an abusive head trauma. This study too, could be conducted as a narrative life history or a phenomenology depending on the number of participants involved. A fourth recommendation would be to conduct further studies on resilience mechanisms used to cope with living with an abusive head trauma. A final recommendation would be to compare the life history of a survivor of an abusive head trauma to that of someone with other types of disabilities, including those with physical and/or cognitive deficits, specifically focusing on resilience mechanisms utilized to cope with those deficits.

### **Summary**

The purpose of this narrative study was to describe the lived experiences of an adolescent survivor of an abusive head trauma living in the Southeastern United States. Trudy was a normally developing infant until her teen-aged, biological father, to gain a temporary reprieve from her inconsolable crying, made the decision to inflict an injury on her that would affect the

rest of her life and the lives of those who love her. Trudy's injury was completely preventable and may have been avoided if her young father, like her teen-aged mother, had been required to participate in a prevention program to address coping mechanisms for dealing with inconsolable crying prior to Trudy's birth. However, Trudy will live with neurological, cognitive, behavioral, academic and social challenges for the remainder of her life. Fortunately, Trudy's mother has formed a large support network that has worked together to help cultivate a sense of self-efficacy in Trudy that allows her to persevere in the face of adversity and Trudy has come to rely on her faith in God to guide her through her toughest challenges. This resilient spirit has carried Trudy through difficulties in her past, present and will continue to aid her in the future as she sets new goals and achieves new success.

## References

- Abes, E. S., Jones, S. R., & McEwen, M. K. (2007). Reconceptualizing the model of multiple dimensions of identity: The role of meaning-making capacity in the construction of multiple identities. *Journal of College Student Development, 48*(1), 1-22.
- Aburn, G., Gott, M., & Hoare, K. (2015). What is resilience? An integrative review of the empirical literature. *Journal of Advanced Nursing, 72*(5), 980-1000.  
doi:10.1111/jan.12888
- Adamsbaum, C., Grabar, S., Mejean, N., & Rey-Salmon, C. (2010). Abusive head trauma: Judicial admissions highlight violent and repetitive shaking. *Pediatrics, 126*(3), 546-555.  
doi:10.1542/peds.2009-3647
- Altman, R.L., Canter, J., Patrick, P.A., Daley, N., Butt, N.K., & Brand, D.A. (2011). Parent education by maternity nurses and prevention of abusive head trauma. *Pediatrics, 128*, 1164-1172. doi:10.1542/peds.2010-3260
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice Hall, Inc.
- Barr, R.G., Barr, M., Fujiwara, T., Conway, J., Catherine, N., & Brant, R. (2009). Do educational materials change knowledge and behavior about crying and shaken baby syndrome? A randomized controlled trial. *Canadian Medical Association Journal, 180*(7), 727-733. doi:10.1503/cmaj
- Barr, R. (2012). Preventing abusive head trauma resulting from a failure of normal interaction between infants and their caregivers. *Proceedings of the National Academy of Sciences of the United States of America, 109*, 17294-17301. doi:10.1073/pnas.1121267109

- Bechtel, K., Le, K., Martin, K. D., Shah, N., Leventhal, J. M., & Colson, E. (2011). Impact of an educational intervention on caregivers' beliefs about infant crying and knowledge of shaken baby syndrome. *Academic Pediatrics, 11*(6), 481-486.  
doi:10.1016/j.acap.2011.08.001
- Benight, C.C., Bandura, A. (2004). Social cognitive theory of posttraumatic recovery: the role of perceived self-efficacy. *Behaviour Research and Therapy, 42*(10), 1129-1148, ISSN 0005-7967, doi:10.1016/j.brat.2003.08.008.
- Brands, I., Stapert, S., Köhler, S., Wade, D., & van Heugten, C. (2015). Life goal attainment in the adaptation process after acquired brain injury: The influence of self-efficacy and of flexibility and tenacity in goal pursuit. *Clinical Rehabilitation, 29*(6), 611-622.  
doi:10.1177/0269215514549484
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Bruner, J.S. (1960). *The process of education*. Cambridge, MA: Belknap Press.
- Bruner, J.S. (1966). *Toward a theory of instruction*. Cambridge, MA: Harvard University Press.
- Carr, D. (1986). *Time, narrative, and history*. Bloomington, IN: Indiana University Press.
- Cheshire, D. J., Buckley, V. A., Leach, S. L., Scott, R. A., & Scott, K. K. (2015). Navigating the terrain in the identification and program development for children with mild traumatic brain injuries. *School Psychology Forum, 9*(3), 199-213.
- Chevignard, M., & Lind, K. (2014). Long-term outcome of abusive head trauma. *Pediatric Radiology, 44*, 548-558. doi:10.1007/s00247-014-3169-8.

- Chu, Y., Brown, P., Harniss, M., Kautz, H., & Johnson, K. (2014). Cognitive support technologies for people with TBI: current usage and challenges experienced. *Disability and Rehabilitation Assistive Technology*, 9(4), 279-285.  
doi:10.3109/17483107.2013.823631.
- Clandinin, D.J. (2013). *Engaging in narrative inquiry*. Walnut Creek, CA: Left Coast Press, Inc.
- Clandinin, D.J. & Connelly, F.M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco, CA: Jossey-Bass
- Clandinin, D.J. & Rosiek, J. (2007). Mapping a landscape of narrative inquiry: Borderland spaces and tensions. In D.J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 35-76). Thousand Oaks, CA: Sage Publications.
- Connelly, F.M. & Clandinin, D.J. (2006). Narrative inquiry. In J. Green, G. Camilli, & P. Elmore (Eds.), *Handbook of complementary methods in education research* (3rd ed.) (pp. 477-487). Retrieved from <https://books.google.com/books>
- Creswell, J. W. (2013). *Qualitative inquiry & research design: Choosing among five approaches*. Los Angeles: SAGE Publications.
- Czarniawska, B. (2004). *Narratives in social science research*. London: Sage Publications, Inc.
- Degeneffe, C. E., & Bursnall, S. (2015). Quality of Professional Services following Traumatic Brain Injury: Adult Sibling Perspectives. *Social Work*, 60(1), 19-27.  
doi:10.1093/sw/swu047
- Degeneffe, C. E., & Lee, G. K. (2010). Quality of Life After Traumatic Brain Injury: Perspectives of Adult Siblings. *Journal of Rehabilitation*, 76(4), 27-36.

- Degeneffe, C., & Olney, M. (2010). 'We are the forgotten victims': Perspectives of adult siblings of persons with traumatic brain injury. *Brain Injury*, 24(12), 1416-1427.  
doi:10.3109/02699052.2010.514317
- Díaz-Olavarrieta, C., García-Piña, C. A., Loredó-Abdala, A., Paz, F., García, S. G., & Schilman, A. (2011). Abusive head trauma at a tertiary care children's hospital in Mexico City: A preliminary study. *Child Abuse & Neglect*, 35(11), 915-923.  
doi:10.1016/j.chiabu.2011.05.017
- Driver, S. (2006). Applying physical activity motivation theories to people with brain injuries. *Adapted Physical Activity Quarterly*, 23, 148-162. doi:10.1123/apaq.23.2.148
- Erikson, E.H. (1950). *Childhood and society*. New York, NY: W.W. Norton.
- Erikson, E.H. (Ed.). (1963). *Youth: Change and challenge*. New York, NY: Basic Books.
- Erikson, E.H. (1980). *Identity and the life cycle*. New York, NY: W.W. Norton (Original work published 1959).
- Faul, M., Xu, L., Wald, M.M., Coronado, V.G. (2010). Traumatic brain injury in the United States: Emergency department visits, hospitalizations and deaths 2002–2006. Atlanta, GA: Centers for Disease Control and Prevention, National Center for Injury Prevention and Control
- Fletcher, D., & Sarkar, M. (2013). Psychological resilience: A review and critique of definitions, concepts, and theory. *European Psychologist*, 18(1), 12-23.  
doi:10.1027/1016-9040/a000124

- Fujiwara, T., Yamada, F., Okuyama, M., Kamimaki, I., Shikoro, N., & Barr, R.G. (2012). Effectiveness of educational materials designed to change knowledge and behavior about crying and shaken baby syndrome: A replication of a randomized controlled trial in Japan. *Child Abuse & Neglect*, *36*, 613-620. doi:10.1016/j.chiabu.2012.07.003
- Gauvin-Lepage, J., & Lefebvre, H. (2010). Social inclusion of persons with moderate head injuries: the points of view of adolescents with brain injuries, their parents and professionals. *Brain Injury*, *24*(9), 1087-1097. doi:10.3109/02699052.2010.494593
- Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine De Gruyter.
- Gough, N. (2008). Life stories. In L.M. Given (Ed.), *The Sage Encyclopedia of Qualitative Research Methods* (Vol. 1, p. 484). Retrieved from <https://books.google.com/books>
- Griesbach, G. S., Kreber, L. A., Harrington, D., & Ashley, M. J. (2015). Post-acute traumatic brain injury rehabilitation: Effects on outcome measures and life care costs. *Journal of Neurotrauma*, *32*(10), 704-711. doi:10.1089/neu.2014.3754
- Humphreys, I., Wood, R. L., Phillips, C. J., & Macey, S. (2013). The costs of traumatic brain injury: A literature review. *ClinicoEconomics and Outcomes Research*, *5*, 281-287. doi:10.2147/CEOR.S44625
- Iadevaia, C., Roiger, T., & Zwart, M. B. (2015). Qualitative examination of adolescent health-related quality of life at 1 year postconcussion. *Journal of Athletic Training (Allen Press)*, *50*(11), 1182-1189. doi:10.4085/1062-6050-50.11.02
- Individuals with Disabilities Education Improvement Act (IDEIA), 20 U.S.C. § 1400 (2004).
- Jones, S. R., & McEwen, M. K. (2000). A conceptual model of multiple dimensions of identity. *Journal of College Student Development*, *41*(4), 405-414.



- Kadom, N., Khademian, Z., Vezina, G., Shalaby-Rana, E., Rice, A., & Hinds, T. (2014). Usefulness of MRI detection of cervical spine and brain injuries in the evaluation of abusive head trauma. *Pediatric Radiology*, *44*(7), 839-48. doi:10.1007/s00247-014-2874-7
- Keenan, A., & Joseph, L. (2010). The needs of family members of severe traumatic brain injured patients during critical and acute care: a qualitative study. *Canadian Journal of Neuroscience Nursing*, *32*(3), 25-35.
- Keenan, H. T., & Leventhal, J. M. (2010). A case-control study to evaluate Utah's shaken baby prevention program. *Academic Pediatrics*, *10*(6), 389-94. doi:10.1016/j.acap.2010.08.005
- Kirk, S., Fallon, D., Fraser, C., Robinson, G., & Vassallo, G. (2015). Supporting parents following childhood traumatic brain injury: a qualitative study to examine information and emotional support needs across key care transitions. *Child: Care, Health & Development*, *41*(2), 303-313. doi:10.1111/cch.12173
- Lajiness-O'Neill, R. & Erdodi, L.A. (2011). Traumatic brain injury. In J.M. Kauffman & D.P. Hallahan (Eds.), *Handbook of special education* (pp. 262-276). Retrieved from <https://books.google.com/books>
- Lefebvre, H., & Levert, M. J. (2012). The needs experienced by individuals and their loved ones following a traumatic brain injury. *Journal of Trauma Nursing*, *19*(4), 197-207. doi:10.1097/JTN .0b013e318275990d
- Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage Publications

Lind, K., Toure, H., Brugel, D., Meyer, P., Laurent-Vannier, A., & Chevignard, M. (2016).

Extended follow-up of neurological, cognitive, behavioral and academic outcomes after severe abusive head trauma. *Child Abuse & Neglect*, *51*, 358-367.

doi:10.1016/j.chiabu.2015.08.001

Mealings, M., & Douglas, J. (2010). 'School's a big part of your life . . .': Adolescent

perspectives of their school participation following traumatic brain injury. *Brain*

*Impairment*, *11*(1), 1-16. doi:10.1375/brim.11.1.1

Mishler, E.G. (2003). Representing discourse: The rhetoric of transcription. In Y.S. Lincoln &

N.K. Denzin (Eds.), *Turning points in qualitative research: Tying knots in a handkerchief*

(pp. 297-326). Retrieved from <https://books.google.com/books>

Mok, J.Y.Q., Jones, P.A., Myerscough, E., Shah, A.R.F., & Minns, R.A. (2010). Non-accidental

head injury: a consequence of deprivation? *Journal of Epidemiology and Community*

*Health (1979-)*, *64*(12), 1049–1055. doi:10.1136/jech.2009.090217

Oliver, M., Montero, F., Fernández-Caballero, A., González, P., and Molina, J.P. (2015). RGB-D

assistive technologies for acquired brain injury: Description and assessment of user

experience. *Expert Systems*, *32*, 370–380. doi:10.1111/exsy.12096

Parks, S.E., Annett, J.L., Hill, H.A., & Karch, D.L. (2012). Pediatric abusive head trauma:

Recommended definitions for public health surveillance and research. Atlanta, GA:

Centers for Disease Control and Prevention.

Parrish, J., Baldwin-Johnson, C., Volz, M., & Goldsmith, Y. (2013). Abusive head trauma

among children in Alaska: A population-based assessment. *Circumpolar Health*

*Supplements*, *72*, 472-479. doi:10.3402/ijch.v72i0.21216

- Patton, M.Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Peterson, C., Likang, X., Florence, C., Parks, S. E., Miller, T. R., Barr, R. G., & ... Steinbeigle, R. (2014). The medical cost of abusive head trauma in the united states. *Pediatrics*, *134*(1), 91-99. doi:10.1542/peds.2014-0117
- Piaget, J. (1952). *The origins of intelligence in children*. (M. Cook, Trans.) New York, NY: International Universities Press.
- Piaget, J. (1953). *Origins of intelligence in the child*. (M. Cook, Trans.) Retrieved from <http://books.google.com/books> (Original work published 1936).
- Postema, F.A.M., Sieswerda-Hoogendoorn, T., Majoie, C.B.L.M., & van Rijn, R.R. (2014). Age determination of subdural hematomas: Survey among radiologists. *Emergency Radiology*, *21*(4), 349-58. doi:10.1007/s10140-014-1196-2
- Riessman, C.K. (1993). *Narrative analysis*. Newbury Park, CA: Sage Publications, Inc.
- Riessman, C.K. (2008). *Narrative methods for the human sciences*. Thousand Oaks, CA: Sage Publications, Inc.
- Risen, S.R., Suskauer, S.J., DeMatt, E.J., Slomine, B.S., Salorio, C.F. (2014). Functional outcomes in children with abusive head trauma receiving inpatient rehabilitation compared with children with nonabusive head trauma. *The Journal of Pediatrics*, *164*(3), 613-619. doi:10.1016/j.jpeds.2013.10.075
- Schwandt, T.A. (2015). *The Sage dictionary of qualitative inquiry* (4th ed.). Thousand Oaks, CA: Sage Publications, Inc.

- Shanahan, M. E., Nocera, M., Zolotor, A. J., Sellers, C. J., & Runyan, D. K. (2011). Education on abusive head trauma in North Carolina hospitals. *Child Abuse Review, 20*(4), 290-297. doi:10.1002/car.1195
- Simonnet, H., Laurent-Vannier, A., Yuan, W., Hully, M., Valimahomed, S., Bourennane, M., Chevignard, M. (2014). Parents' behavior in response to infant crying: Abusive head trauma education, *Child Abuse & Neglect, (38)* 12, 1914-1922. doi:10.1016/j.chiabu.2014.06.002
- Special Education, Education of Students with Disabilities, South Carolina Code§ 43-243.
- Stewart, T.C., Polgar, D., Gilliland, J., Tanner, D., Girotti, M.J., Parry, N., & Fraser, D.D. (2011). Shaken baby syndrome and a triple-dose strategy for its prevention. *Journal of Trauma, Injury, Infection and Critical Care, 71*, 1801-1807. doi:10.1097/TA.0b013e31823c484a
- Stoll, B., & Anderson, J. K. (2013). Prevention of abusive head trauma: A literature review. *Pediatric Nursing, 39*(6), 300-308.
- Tanoue, K., & Matsui, K. (2015). Differences between abusive head trauma and physical abuse in Japan. *Pediatrics International, 57*(5), 845-848. doi:10.1111/ped.12632
- Todis, B., Glang, A., Bullis, M. E., Ettl, D. & Hood, D. (2011). Longitudinal investigation of the post-high school transition experiences of adolescents with traumatic brain injury. *Journal of Head Trauma and Rehabilitation, 26*(2), 138-149. doi:10.1097/HTR.0b013e3181e5a87a
- Ungar, M., Ghazinour, M., & Richter, J. (2012). Annual research review: What is resilience within the social ecology of human development? *Journal of Child Psychology and Psychiatry, 54*(4), 348-366. doi:10.1111/jcpp.12025

- U.S. Department of Education, Office of Special Education and Rehabilitative Services. (2010). Thirty-five years of progress in educating children with disabilities through IDEA. Retrieved from <https://www2.ed.gov/about/offices/list/osers/idea35/history/idea-35-history.pdf>
- Vu, J. A., Babikian, T., & Asarnow, R. F. (2011). Academic and language outcomes in children after traumatic brain injury: A meta-analysis. *Exceptional Children, 77*(3), 263-281.
- Vygotsky, L.S. (1978). *Mind in society: The development of higher psychosocial processes*. Cambridge, MA: Harvard University Press.
- Walker, C.A. (2015). Social constructionism and qualitative research. *Journal of Theory Construction & Testing, 19*(2), 37-38.
- Wang, J., Ding, D., Teodorski, E. E., Mahajan, H. P., & Cooper, R. A. (2016). Use of assistive technology for cognition among people with traumatic brain injury: A survey study. *Military Medicine, 181*(6), 560-566. doi:10.7205/MILMED-D-14-00704
- Wu, G., Feder, A., Cohen, H., Kim, J.J., Calderon, S., Charney, D.S., & Mathé, A.A. (2013). Understanding resilience. *Frontiers in Behavioral Neuroscience, 7*(10), 1-15. doi:10.3389/fnbeh.2013.00010
- Xiang, J., Junxin, S., Wheeler, K.K., Yeates, K.O., Taylor, H.G., & Smith, G.A. (2013). Pediatric patients with abusive head trauma treated in US Emergency Departments, 2006-2009. *Brain Injury, 27*(13-14), 1555-1561. doi:10.3109/02699052.2013.831126
- Zasler, N.D., Ameis, A., & Riddick-Grisham, S.N. (2013). Life care planning after traumatic brain injury. *Physical Medicine and Rehabilitation Clinics of North America, 24*(3), 445-465.

**APPENDICES****Appendix A: IRB Approval Letter****LIBERTY UNIVERSITY.**  
INSTITUTIONAL REVIEW BOARD

April 28, 2017

Crystal Ledford

IRB Approval 2851.042817: Trudy's Triumph: A Narrative Life History of an Adolescent Survivor of Abusive Head Trauma

Dear Crystal Ledford,

We are pleased to inform you that your study has been approved by the Liberty University IRB. This approval is extended to you for one year from the date provided above with your protocol number. If data collection proceeds past one year, or if you make changes in the methodology as it pertains to human subjects, you must submit an appropriate update form to the IRB. The forms for these cases were attached to your approval email.

Thank you for your cooperation with the IRB, and we wish you well with your research project.

Sincerely,

**G. Michele Baker, MA, CIP**  
*Administrative Chair of Institutional Research*  
**The Graduate School**

**LIBERTY**  
UNIVERSITY.  
*Liberty University | Training Champions for Christ since 1971*

## Appendix B: Consent Form

The Liberty University Institutional  
Review Board has approved  
this document for use from  
4/28/2017 to 4/27/2018  
Protocol # 2851.042817

### CONSENT FORM

#### TRUDY'S TRIUMPH: A NARRATIVE LIFE HISTORY OF AN ADOLESCENT SURVIVOR OF ABUSIVE HEAD TRAUMA

Crystal G. Ledford  
Liberty University  
School of Education

I am conducting a research study to learn what life is like for a teen survivor of an abusive head trauma. You are invited to be in this study because you are a teen survivor of an abusive head trauma or you are a family member or friend of a teen survivor of an abusive head trauma. I ask that you read this form and ask any questions you have before agreeing to be in the study.

Crystal G. Ledford, a doctoral candidate in the School of Education at Liberty University, is conducting this study.

**Background Information:** The purpose of this narrative study is to describe the life history of an adolescent survivor of an abusive head trauma in the Southeastern United States.

**Procedures:** If you agree to be in this study, I would ask you to do the following things: 1. Participate in at least one interview, which will last no more than one hour and will be audio recorded; 2. Allow me to participate in events and celebrations that would help me understand the life of a teen survivor of an abusive head trauma; 3. Discuss your experiences with surviving an abusive head trauma or being the family member or friend of a survivor of an abusive head trauma; 4. Provide copies of documents and other objects that would show what life is like for a teen survivor of an abusive head trauma.

**Risks and Benefits of being in the Study:** The risks involved with participating in this study are no more than the participant would encounter in everyday life. However, if I become aware of information that meets the mandatory reporting requirements for child abuse, child neglect, or intent to harm self or others, I will report the information immediately and end the study.

There are no direct benefits to participation in this study.

**Compensation:** You will not be paid to participate in this study.

**Confidentiality:** The records of this study will be kept private. You will not be identified in my study or any other report that I write. The names of places, as well as all participants will be changed to pseudonyms. Research records, as well as audio recordings, will be stored in a locked file box and in password protected digital files in my home, and only I will have access to the records. After three years, all collected information will be destroyed. Digital files, including audio recordings will be deleted, and all paper files will be shredded and disposed of.

**Voluntary Nature of the Study:** Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with Liberty University. If you decide to participate, you are free to not answer any question or drop out of the study at any time without affecting those relationships.

The Liberty University Institutional  
Review Board has approved  
this document for use from  
4/28/2017 to 4/27/2018  
Protocol # 2851.042817

**How to Withdraw from the Study:** If you choose to stop being part of the study, please tell me. If you choose to no longer participate, information collected from you will be destroyed immediately and will not be included in this study.

**Contacts and Questions:** The researcher conducting this study is Crystal G. Ledford. You may ask any questions you have now. If you have questions later, please contact me at (864) 3992381 or by email at cgledford@liberty.edu. You may also contact my faculty advisor, Dr. Gail Collins, at gcollins2@liberty.edu.

If you have any questions or concerns about this study and would like to talk to someone other than me, please contact the Institutional Review Board, 1971 University Blvd, Lynchburg, VA 24515 or email at irb@liberty.edu.

Please tell me if you would like a copy of this form to keep for your records.

**Statement of Consent:** I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.

The researcher has my permission to audio-record me as part of my participation in this study.

---

Signature

Date

---

Signature of Investigator

Date



## Appendix C: Parent Consent & Child Assent Form

The Liberty University Institutional  
Review Board has approved  
this document for use from  
4/28/2017 to 4/27/2018  
Protocol # 2851.042817

### PARENT CONSENT & CHILD ASSENT FORM

#### TRUDY'S TRIUMPH: A NARRATIVE LIFE HISTORY OF AN ADOLESCENT SURVIVOR OF ABUSIVE HEAD TRAUMA

Crystal G. Ledford  
Liberty University  
School of Education

I am conducting a research study to learn about what life is like for a teen survivor of an abusive head trauma. Your child is invited to be in this study because she is the sister of someone who has experienced this. I ask that you read this form and ask any questions you may have before agreeing to allow her to be in the study.

Crystal G. Ledford, a doctoral candidate in the School of Education at Liberty University, is conducting this study.

**Background Information:** The purpose of this study is to investigate the life history of an adolescent survivor of an abusive head trauma, including the challenges she faces and the coping skills she uses to overcome those challenges.

**Procedures:** If you agree to allow your child to be in this study, I will ask her some questions about her sister. I want to know what types of challenges she thinks her sister faces and how she sees her sister deal with things that are hard for her. I will also ask her to share anything, like letters, photos, or artwork, that she thinks would be helpful to understand who her sister is.

#### **Risks and Benefits of being in the Study:**

The risks involved with participating in this study are no more than the participant would encounter in everyday life.

There are no direct benefits to participation in this study.

**Compensation:** Your child will not be paid for participating in this study.

**Confidentiality:** The records of this study will be kept private. Your child will not be able to be identified in any reports I write. The names of places, as well as all participants will be changed to pseudonyms. Research records, as well as audio recordings, will be stored in a locked file box and in password protected digital files in my home, and I will have access to the records. After three years, all information will be destroyed. Digital files, including audio recordings, will be deleted, and all paper files will be shredded and disposed of.

The Liberty University Institutional  
Review Board has approved  
this document for use from  
4/28/2017 to 4/27/2018  
Protocol # 2851.042817

**Voluntary Nature of the Study:** Participation in this study is voluntary. Your decision whether or not to allow your child to participate will not affect her current or future relations with Liberty University. If you decide to allow your child to be in this study, she is free to ask questions at any time. She is also free not to answer any question or drop out of the study at any time without affecting those relationships.

**How to Withdraw from the Study:** If your child chooses to stop being part of the study, you or your child should tell me. If your child chooses to stop being part of the study, information collected from her will be destroyed immediately and will not be used in this study. **Contacts and Questions:** The researcher conducting this study is Crystal G. Ledford. Please ask any questions you have now. If you have questions later, please to contact me at (864) 399-2381 or by email at cgledford@liberty.edu. You may also contact my advisor, Dr. Gail Collins, at gcollins2@liberty.edu.

If you have any questions or concerns about this study and would like to talk to someone other than me, please contact the Institutional Review Board, 1971 University Blvd, Lynchburg, VA 24515 or email at irb@liberty.edu.

*Please tell me if you would like a copy of this form to keep for your records.*

**Statement of Consent:** I have read and understood the above information. I have asked questions and have received answers. I consent to allow my child to participate in the study.

The researcher has my permission to audio-record my child/student as part of her participation in this study.

---

Signature of Minor

Date

---

Signature of Parent

Date

---

Signature of Investigator

Date

## Appendix D: Observation Protocol

### Observation Excerpt

Date & Time: Sat., 5/27/17 afternoon  
Event: Family Camping Trip w/Trudy's fam.  
Participants: Trudy, Kirsten, Waylon, Karly,  
 me, my husband & two children  
Setting/Place: Lake M Campground  
Notes:  
 This afternoon, we all decided to go geocaching, which is something that Trudy and her family enjoy doing on their camping trips. While on our walk, Trudy talked about her job training experiences. She told me that she didn't like working at the daycare because she didn't know any of the adults there and they didn't help her to know what to do. She told me about working in the thrift shop and said she likes doing that because she likes to sort things. She also said she has a hard time with the clothes sorting because she can't see well enough to see the sizes or the spots on the clothing. When we returned from our walk, she helped to get food ready for supper. She seems to want to be around the adults more than the kids.

Time: Saturday evening 5/27/17  
 Trudy did not take her ADHD med. this morning and she is laughing a lot tonight. We played the Jelly Bean game where you eat jelly beans and some are gross. The faces she made when she got a gross one have been hilarious! We have all had a lot of belly laughs.

## Appendix E: Email Permission to Use M. Chevignard Study

### Permission to use your study

M

Thu 1/19, 8:34 AM

Hi,

Yes of course no problem for me

But if you do not just take a picture of the table in the paper to include it in the dissertation I imagine it is fine?

Best regards

MC

---

Docteur Mathilde Chevignard

Praticien Hospitalier

Service de Rééducation des Pathologies Neurologiques de l'Enfant

Pôle de Rééducation et Réadaptation de l'Enfant

Hôpitaux de Saint Maurice

LG

Ledford, Crystal Gayle

Reply |

Wed 1/18, 11:28 PM

Sent Items

Sent Items

Dr. Chevignard,

I hope this email finds you well. I am currently writing a doctoral dissertation focusing on the narrative life history of an adolescent survivor of an abusive head trauma in the Southeastern United States. I would like your permission to adapt the information regarding the Glasgow Outcome Scale included in your article, "Long-term outcome of abusive head trauma," by M.P. Chevignard and K. Lind, 2014, *Pediatric Radiology*, 44, p.550, as depicted below.

Table 1

#### *Glasgow Outcome Scale*

Scale Score	Category	Characteristics
1	Good outcome	Age-appropriate levels of cognitive functioning; School-aged functioning without special education
2	Moderate disability	Significant reduction in cognitive functioning; engaged in special education therapy; and/or motor deficits interfere with daily living

3	Severe disability	Deficient cognitive functioning; and/or severe motor deficits; requires substantial assistance with self-care skills
4	Persistent vegetative state	No evidence of verbal or nonverbal communication; unresponsive to commands
5	Death	

---

I would like to extend my sincerest appreciation for your consideration.

Kindest regards,  
Crystal G. Ledford  
Doctoral Student

**Appendix F: Reflective Journal**

<b>Date and Time:</b>	
<b>Objective Summary:</b>	<b>Subjective Reflection:</b>

Appendix G: Hospital Photos



## Appendix H: Medical Record I


February 23, 1998

Financing Administration		CMB NO. 0507007		
ADDENDUM TO:		<input type="checkbox"/> PLAN OF TREATMENT	<input checked="" type="checkbox"/> MEDICAL UPDATE	
1. Patient's HI Claim No.	2. SOC Date	3. Certification Period		4. Medical Record No.
	022398	From: 022398	To: 042398	5. Provider No.
Patient's Name _____				
Item No.	7.			
16	<p>a 4-month old infant that has been subjected to shaken baby syndrome. As a result she sustained a Fx. Skull, bilateral cerebral hemorrhages and bilateral retinal hemorrhages w/retinal detachments. During hospitalization, she received surgery to relieve the bilateral cerebral hematomas. Mother states that _____ cannot currently see and the family was informed that it is uncertain about how much sight she will regain if any. Most of home visit _____ was intermittently irritable. Vital Signs stable with Temp 98.2 ax, HR) 144, RR) 48. Otherwise, _____ seemed healthy with good bowel sounds and taking in adequate nutrition. The mother and grandparents are very supportive and work together to make sure they follow the physician's orders. There is a dressing on upper neck. No orders to change upon admission.</p> <p>Reason Homebound: Receiving IV antibiotics.</p>			



Appendix I: Medical Record 2

March 13, 1998

Clinical Encounter Form																																													
<b>Reason For Visit:</b> 6 month physical - 3-13-98 Flw of pressure ulcer, GE reflux, and hospitalization for shaken baby syndrome.																																													
<b>Current Medications/Treatment/Allergies</b> Tegretol 1.75 cc po q 12h <span style="float: right;">NKDA</span> Reglan 5/5 0.17 ml po q 6h Zantac 75/5 0.47 mg po q 6h Augmentin 200/5 4.0 ml po BID x 14 days	<b>Interval History</b> 6 months old ± GE reflux and h/o pulmonary contusion, rib fracture + skull fracture s/p MVA in 12-97, Now with Admit s/p shaken baby syndrome with <u>Ⓟ</u> retinal hemorrhages and subdural hematoma. Seizures in PICU but none since.																																												
<b>Assessment</b> Age <u>6m</u> Hgt <u>24 3/4</u> in Wgt <u>15 lb 13oz</u> Head Circumference <u>16 1/8</u> in BP <u>not done</u> Temp. <u>97.9</u> LMP <u>Not Applicable</u> Vision (R <u>      </u> L <u>      </u> ) Hearing (R <u>      </u> L <u>      </u> ) <span style="font-size: small;">(cannot assess) probably blind perceptually</span>																																													
	<table border="0" style="width:100%;"> <tr> <td style="width: 10%;"><b>WNL</b></td> <td style="width: 10%;"><b>Detail</b></td> <td style="width: 80%;"><b>Abnormal Findings</b></td> </tr> <tr> <td>HEENT</td> <td><input type="checkbox"/></td> <td>well healed scars s/p surgery 2 to drain subdural hematoma, <u>Ⓟ</u> amblyopia</td> </tr> <tr> <td>Neck/Thyroid</td> <td><input type="checkbox"/></td> <td>hearing pressure same on occiput</td> </tr> <tr> <td>Lungs</td> <td><input checked="" type="checkbox"/></td> <td></td> </tr> <tr> <td>Heart</td> <td><input checked="" type="checkbox"/></td> <td></td> </tr> <tr> <td>Breast</td> <td><input checked="" type="checkbox"/></td> <td></td> </tr> <tr> <td>Abdomen</td> <td><input checked="" type="checkbox"/></td> <td></td> </tr> <tr> <td>Extremities</td> <td><input checked="" type="checkbox"/></td> <td></td> </tr> <tr> <td>Neuromuscular</td> <td><input type="checkbox"/></td> <td>s/p retinal hemorrhages - probably blind. Not rolling over yet - bring hands to midline. <u>Ⓟ</u> palmar grasp.</td> </tr> <tr> <td>Skin</td> <td><input type="checkbox"/></td> <td>see above.</td> </tr> <tr> <td>Lymph Nodes</td> <td><input checked="" type="checkbox"/></td> <td></td> </tr> <tr> <td>Rectum</td> <td><input checked="" type="checkbox"/></td> <td></td> </tr> <tr> <td>Genitalia</td> <td><input checked="" type="checkbox"/></td> <td></td> </tr> </table>	<b>WNL</b>	<b>Detail</b>	<b>Abnormal Findings</b>	HEENT	<input type="checkbox"/>	well healed scars s/p surgery 2 to drain subdural hematoma, <u>Ⓟ</u> amblyopia	Neck/Thyroid	<input type="checkbox"/>	hearing pressure same on occiput	Lungs	<input checked="" type="checkbox"/>		Heart	<input checked="" type="checkbox"/>		Breast	<input checked="" type="checkbox"/>		Abdomen	<input checked="" type="checkbox"/>		Extremities	<input checked="" type="checkbox"/>		Neuromuscular	<input type="checkbox"/>	s/p retinal hemorrhages - probably blind. Not rolling over yet - bring hands to midline. <u>Ⓟ</u> palmar grasp.	Skin	<input type="checkbox"/>	see above.	Lymph Nodes	<input checked="" type="checkbox"/>		Rectum	<input checked="" type="checkbox"/>		Genitalia	<input checked="" type="checkbox"/>						
<b>WNL</b>	<b>Detail</b>	<b>Abnormal Findings</b>																																											
HEENT	<input type="checkbox"/>	well healed scars s/p surgery 2 to drain subdural hematoma, <u>Ⓟ</u> amblyopia																																											
Neck/Thyroid	<input type="checkbox"/>	hearing pressure same on occiput																																											
Lungs	<input checked="" type="checkbox"/>																																												
Heart	<input checked="" type="checkbox"/>																																												
Breast	<input checked="" type="checkbox"/>																																												
Abdomen	<input checked="" type="checkbox"/>																																												
Extremities	<input checked="" type="checkbox"/>																																												
Neuromuscular	<input type="checkbox"/>	s/p retinal hemorrhages - probably blind. Not rolling over yet - bring hands to midline. <u>Ⓟ</u> palmar grasp.																																											
Skin	<input type="checkbox"/>	see above.																																											
Lymph Nodes	<input checked="" type="checkbox"/>																																												
Rectum	<input checked="" type="checkbox"/>																																												
Genitalia	<input checked="" type="checkbox"/>																																												
<table border="0" style="width:100%;"> <tr> <td style="width: 25%;"><b>Vulva</b></td> <td style="width: 25%;"><b>Vagina</b></td> <td style="width: 25%;"><b>Cervix</b></td> <td style="width: 25%;"><b>Uterus/Adnexa</b></td> </tr> <tr> <td><input checked="" type="checkbox"/> WNL</td> <td><input checked="" type="checkbox"/> WNL</td> <td><input checked="" type="checkbox"/> WNL <u>Not Examined</u></td> <td><input checked="" type="checkbox"/> WNL <u>Not Examined</u></td> </tr> <tr> <td><input type="checkbox"/> Erythema</td> <td><input type="checkbox"/> Discharge</td> <td><input type="checkbox"/> Discharge</td> <td><input type="checkbox"/> Cervical Motion Tenderness</td> </tr> <tr> <td><input type="checkbox"/> Edema</td> <td><input type="checkbox"/> Erythema</td> <td><input type="checkbox"/> Erythema</td> <td><input type="checkbox"/> Uterine Tenderness</td> </tr> <tr> <td><input type="checkbox"/> Lesion</td> <td><input type="checkbox"/> Lesion</td> <td><input type="checkbox"/> Friable</td> <td><input type="checkbox"/> Adnexal Tenderness</td> </tr> <tr> <td><input type="checkbox"/> Warts</td> <td><input type="checkbox"/> Warts</td> <td><input type="checkbox"/> Lesions</td> <td><input type="checkbox"/> Mass</td> </tr> <tr> <td></td> <td></td> <td></td> <td><input type="checkbox"/> Size</td> </tr> <tr> <td></td> <td></td> <td></td> <td><input type="checkbox"/> Position</td> </tr> </table>	<b>Vulva</b>	<b>Vagina</b>	<b>Cervix</b>	<b>Uterus/Adnexa</b>	<input checked="" type="checkbox"/> WNL	<input checked="" type="checkbox"/> WNL	<input checked="" type="checkbox"/> WNL <u>Not Examined</u>	<input checked="" type="checkbox"/> WNL <u>Not Examined</u>	<input type="checkbox"/> Erythema	<input type="checkbox"/> Discharge	<input type="checkbox"/> Discharge	<input type="checkbox"/> Cervical Motion Tenderness	<input type="checkbox"/> Edema	<input type="checkbox"/> Erythema	<input type="checkbox"/> Erythema	<input type="checkbox"/> Uterine Tenderness	<input type="checkbox"/> Lesion	<input type="checkbox"/> Lesion	<input type="checkbox"/> Friable	<input type="checkbox"/> Adnexal Tenderness	<input type="checkbox"/> Warts	<input type="checkbox"/> Warts	<input type="checkbox"/> Lesions	<input type="checkbox"/> Mass				<input type="checkbox"/> Size				<input type="checkbox"/> Position	<table border="0" style="width:100%;"> <tr> <td style="width: 25%;"><b>Penis</b></td> <td style="width: 25%;"><b>Scrotum</b></td> </tr> <tr> <td><input checked="" type="checkbox"/> WNL <u>NA</u></td> <td><input type="checkbox"/> WNL</td> </tr> <tr> <td><input type="checkbox"/> Discharge</td> <td><input type="checkbox"/> Tenderness</td> </tr> <tr> <td><input type="checkbox"/> Lesions</td> <td><input type="checkbox"/> Edema</td> </tr> <tr> <td><input type="checkbox"/> Swelling</td> <td><input type="checkbox"/> Rash</td> </tr> <tr> <td><input type="checkbox"/> Warts</td> <td><input type="checkbox"/> Mass</td> </tr> </table>	<b>Penis</b>	<b>Scrotum</b>	<input checked="" type="checkbox"/> WNL <u>NA</u>	<input type="checkbox"/> WNL	<input type="checkbox"/> Discharge	<input type="checkbox"/> Tenderness	<input type="checkbox"/> Lesions	<input type="checkbox"/> Edema	<input type="checkbox"/> Swelling	<input type="checkbox"/> Rash	<input type="checkbox"/> Warts	<input type="checkbox"/> Mass
<b>Vulva</b>	<b>Vagina</b>	<b>Cervix</b>	<b>Uterus/Adnexa</b>																																										
<input checked="" type="checkbox"/> WNL	<input checked="" type="checkbox"/> WNL	<input checked="" type="checkbox"/> WNL <u>Not Examined</u>	<input checked="" type="checkbox"/> WNL <u>Not Examined</u>																																										
<input type="checkbox"/> Erythema	<input type="checkbox"/> Discharge	<input type="checkbox"/> Discharge	<input type="checkbox"/> Cervical Motion Tenderness																																										
<input type="checkbox"/> Edema	<input type="checkbox"/> Erythema	<input type="checkbox"/> Erythema	<input type="checkbox"/> Uterine Tenderness																																										
<input type="checkbox"/> Lesion	<input type="checkbox"/> Lesion	<input type="checkbox"/> Friable	<input type="checkbox"/> Adnexal Tenderness																																										
<input type="checkbox"/> Warts	<input type="checkbox"/> Warts	<input type="checkbox"/> Lesions	<input type="checkbox"/> Mass																																										
			<input type="checkbox"/> Size																																										
			<input type="checkbox"/> Position																																										
<b>Penis</b>	<b>Scrotum</b>																																												
<input checked="" type="checkbox"/> WNL <u>NA</u>	<input type="checkbox"/> WNL																																												
<input type="checkbox"/> Discharge	<input type="checkbox"/> Tenderness																																												
<input type="checkbox"/> Lesions	<input type="checkbox"/> Edema																																												
<input type="checkbox"/> Swelling	<input type="checkbox"/> Rash																																												
<input type="checkbox"/> Warts	<input type="checkbox"/> Mass																																												
<b>Additional Comments:</b> Currently receives OT and PT. Could benefit from neurology clinic + help w/ Tegretol (last level B.16 on Feb 10, 1998). Dad is alleged perpetrator and not allowed any contact with child.																																													
Signature of Examiner: _____	Client's ID Number _____ Client's Name _____ Date of Birth <u>9-16-97</u>																																												
<b>DATE OF VISIT:</b> <u>3-13-98</u>																																													

### Appendix J: First Individualized Education Plan Excerpt

#### CENTER FOR SPECIAL CHILDREN INDIVIDUALIZED EDUCATION PROGRAM

Date: September 1998 Chronological Age: 12 months  
 Name:            DOB: 9/16/97  
 Parent(s)    Address:     
 Teacher:   

#### PRESENT LEVELS OF EDUCATIONAL PERFORMANCE

Areas of Assessment	*Method of Assessment	Date	Findings/Observations
Cognitive	Hawaii Early Learning Profile Checklist	Sept '98	Skills scattered, 6-10 months. Strengths - Good play attending skills. Plays with a toy for 2-3 minutes. Imitates familiar gestures such as patting and banging. Demonstrated good sound awareness and localization skills. Found hidden object under a screen. Beginning to use locomotion to regain object. Guides action on toy manually. Needs: Exposure to different appropriate play activities.
Social/Emotional	Hawaii Early Learning Profile Checklist		Skills Scattered 6-9 months. Strengths: Happy, alert, sociable and determined little girl. socializes with any adult. She lifts arms to be picked up. Explores adult features and is beginning to explore objects within a few feet out of her reach. Responds playful to mirror. Needs: Exposure to different social situations.

\* Indicates name of test, observation/checklist, or other method of assessment

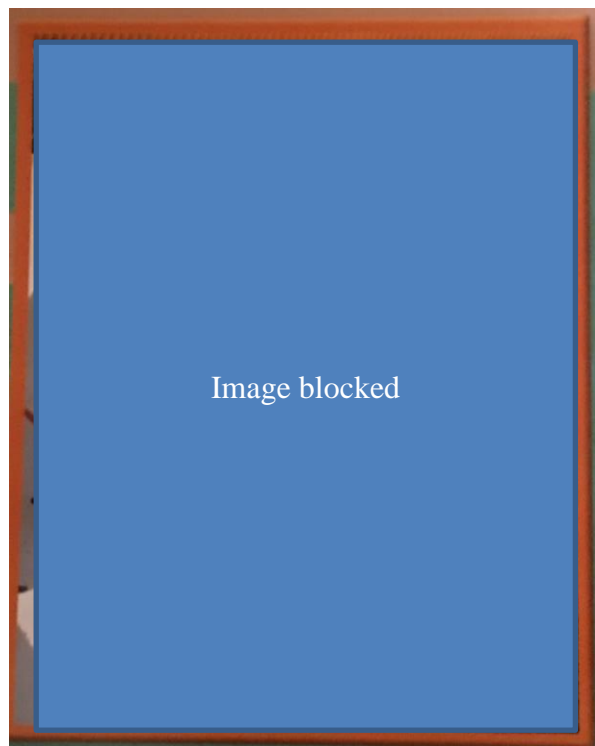
## Appendix K: Occupational Diploma Requirements

### Graduation Requirements

- Occupational Prep (incl. Career Lab) 4 Units
- Occupational English B 4 Units
- Occupational Math B 4 Units
- Occupational Science 3 Units
- Occupational Social Studies 2 Units
- Health/PE (or equivalent) 1 Unit
- Electives (incl. Work Exp.) 6 Units
- Total Units Required for Graduation 24 Units
- 10 days or more Supervised Work Sampling
- 360 Hours of Work Experience
- 20 Hours of Community Services
- 30 Hours in Career Lab
- Senior Venture: Career Portfolio/Presentation



### Appendix L: Trudy's Baseball Photos



**Appendix M: Project SEARCH Acceptance Letter**

**Congratulations!** In recognition of your exceptional achievements and hard work during your interview process, you have been selected from a very competitive group of candidates to participate in the Project SEARCH program at [REDACTED] Health System for the 2017 to 2018 school year. We look forward to working with you as you make the challenging transition from school to the work force. Please read the additional materials with your parents, included in this envelope. Exciting vocational opportunities await you at [REDACTED]!

As a Catholic health ministry, [REDACTED] offers the diversity of a large hospital system while maintaining the personalized care for each and every patient. We are confident that the opportunities to work alongside the outstanding [REDACTED] Family will have a significant impact on both your social and vocational skill growth. You have already demonstrated great capacity as a student and we are convinced you will make a difference at [REDACTED].

We look forward to your first day of internship. Congratulations on your impressive accomplishments.

## Appendix N: Excerpts from Trudy's Final IEP

**Student interests and preferences:** Based on a teacher interview and observations, is interested in helping others and interacting with peers and adults.

Postsecondary Goal(s) that cover **education or training, employment** and as needed, **independent living**. Upon exiting high school the student will:

**Education or training goals:**

Participate in Project SEARCH and receive on the job (non-paid) training with focus on transition to competitive employment with collaboration with adult service agencies.

**Employment goals:**

Upon completion of Project SEARCH program, will be prepared for employment in her community in the field of Human Services.

**Independent living goals:**

will be more independent by demonstrating skills associated with competitive employment including the use of strategies that assist in successfully completing tasks associated with her job.

**Interagency linkage is needed:**

Department of Disabilities and Special Needs (DDSN)  
South Carolina Vocational Rehabilitation Department (SCVRD)

**SC Career Cluster:**

Transportation, Distribution and Logistics

**Course of Study:**

Occupational Course of Study

**Recommended courses to support postsecondary transition:**

will take courses required for the Occupational Credential in order to increase her independence and skills required for competitive employment. In 2017-2018 school year, will participate in Project SEARCH program and be enrolled in courses supporting her outcome of an Occupational Credential and pursuing competitive employment.

**Describe specific directions, considerations, or delivery methods for special education and/or related services:**

For the 2017-2018 school year, has been accepted as an intern in the Project SEARCH program located at hospital downtown. She will have direct instruction in the Project SEARCH curriculum in a special education setting and also participate in three 10-week internships working on soft job skills, self-determination, adult independence, and competitive employment in the hospital environment. There will be intermittent support in the internship through a special education teacher and/or support staff to acquire new skills, learn new tasks and routines; with the outcome of completing these tasks independently.

### Appendix O: Enumeration Chart

Repeated Words/Phrases	Researcher Assigned Codes	Data Collection Source
challenges/challenging	C	Interviews, Observations, Documents/Artifacts
difficult	C	Interviews, Documents/Artifacts
hard	C	Interviews, Documents/Artifacts, Audio-Visual Journal
frustrated/frustrating	C	Interviews, Observations, Documents/Artifacts, Audio-Visual Journal
cope/coping	R	Observations, Documents/Artifacts
overcome/overcame	R	Interviews, Documents/Artifacts
persevere/perseverance	R	Interviews, Observations, Documents/Artifacts
handle	R	Interviews, Audio-Visual Journal
deal	R	Interviews, Audio-Visual Journal
support	R	Interviews, Observations, Documents/Artifacts
help/helpful	R	Interviews, Observations, Documents/Artifacts, Audio-Visual Journal

C = Challenges      R = Resilience

### Appendix P: Challenges Sub-Themes Enumeration Chart

Sub-Theme	Repeated Words/Phrases
Social	leaving school change driving cooking
Cognitive	dressing appropriately living independently playing games doesn't make sense forgetting things can't remember
Behavioral	gives up at first crying anger hurt feelings temper tantrums irritated frustrated
Neurological	seizures detached retinas blindness vision issues can't see good
Academic	walking problems reading problems counting money spelling problems bad handwriting



### Appendix Q: Resilience/Coping Mechanisms Sub-Themes Enumeration Chart

Sub-Theme	Repeated Words/Phrases
support network	good mother good support system support from her parents accountable everybody helps large network
adaptive behavior	expect her to do her best adjusts her head sits close to the screen mimicking her friend talks through her problems calming herself makes lists fewer steps
faith	I pray talk to God God blessed me loves church
perseverance	I got up with it ask for help till I get it self-motivated “can’t” is a bad word keep trying gives her best