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# Transition experiences of selected emerging adults with emotional and behavioral difficulties in higher education

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Transition Experiences of Selected Emerging Adults  
With Emotional and Behavioral Difficulties in Higher Education

by

Kathleen M. Fowler

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
Department of Special Education  
College of Education  
University of South Florida

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# TRANSITION EXPERIENCES OF SELECTED EMERGING ADULTS WITH EMOTIONAL AND BEHAVIORAL DIFFICULTIES

Kathleen M. Fowler

## ABSTRACT

Transitioning into adulthood is an exciting and challenging time for emerging adults, and is even more difficult for young adults with emotional and behavioral difficulties (EBD). Even though the number of transition-aged individuals with EBD is significant, few studies have explored the experiences of this population engaged in educational activities, and there is limited information regarding the personal experiences of emerging adults with EBD. The purpose of the study is to acquire a better understanding of the experiences of young adults diagnosed with an EBD who are working toward their academic goals. Further, this study may give voice to individuals who have not had the opportunity to share their experiences and beliefs.

The researcher employed phenomenological research methods for this study. The purpose of phenomenology is to describe, rather than explain phenomena (Ehrich, 2003). Five participants, aged 18 to 25, and diagnosed with an Axis I disorder in the DSM-IV-TR, were selected using purposeful sampling. The researcher conducted one in-depth interview with the participants, and a brief follow up interview. Data were analyzed using the following seven steps: preliminary grouping, reduction and elimination, clustering the invariant constituents, identification and validation of the invariant constituents and

themes by application, construction of an analysis and development of impressions of each participant, and construction of a composite description of the meanings and essences of the experience, representing the group as a whole.

Although living with an EBD is a “continuous struggle,” it also provides opportunities for feelings of success and empowerment. Salient aspects of living with an EBD include its effect on the self, impact on relationships, and managing treatment, such as medication and therapy. Participants also discussed how EBD impacts their transition experiences and their ability to achieve their goals; relevant themes included academic challenges, issues regarding seeking assistance, and their selection of career choices. The participants are able to manage these challenges because of the supports they have received and coping strategies they have developed. Furthermore, their own personality traits, such as determination, belief in themselves, and goal orientation have been integral in their journey towards achieving their academic and career goals.

## CHAPTER ONE

### INTRODUCTION

#### Statement of Problem

Transitioning into adulthood is a challenging and exciting experience for many, if not most, young adults. The passage from adolescence to adulthood in American culture involves completing school, developing a network of friends, contributing to the maintenance and support of a household, finding fulfilling work, and participating as a member in a community (Clark & Davis, 2000). This transition is more difficult for emerging adults<sup>1</sup> with emotional and behavioral difficulties (EBD) because the skills needed for successful transition are often impaired (Cheney, Malloy, & Hagner, 1998; Davis & Vander Stoep, 1997; McGorry, Edwards, Mihalopoulos, Harrigan, & Jackson, 1996). Young adults with EBD may experience unemployment, substance abuse, incarceration, unnecessary disability, homelessness, and suicide (Davis & Vander Stoep, 1997; D'Amico & Blackorby, 1992; Koerner, 2005; Maag & Katsiyannis, 1998; Massey, 2004). Indeed, “individuals with emotional and behavioral disorders (EBD) experience the least favorable outcomes of any group of individuals with disabilities” (Jolivette, Stichter, Nelson, Scott, & Liapousin, 2000, p. 2). Specifically, young adults with EBD are

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<sup>1</sup> For the purpose of this study, the terms early adulthood, young adulthood, and emerging adulthood will be used interchangeably, while recognizing that Arnett (2006) asserts that emerging adulthood is a new and distinct stage in the life course, and transition to adulthood is just one aspect of this stage.

13.7 times less likely to complete secondary school; 4.1 times less likely to be employed or in college or trade school; 3.1 times more likely to be involved in a criminal activity, and 6.5 times more likely to have gotten or gotten someone pregnant than the non-psychiatric adolescent. (Vander Stoep et al., 2000, p. 352)

Prevalence rates of individuals with EBD vary in the literature, due to inconsistency in how disabilities are defined and measured. However, most estimates of young adults (ages 16-25) with a mental or psychiatric disorder range from 18% to 23% (Aalto-Setala, Marttunen, Tuulio-Henriksson, Poikolainen, & Lonnqvist, 2001; Cohen, Provet, & Jones, 1996; Friedman, 1996). This number is consistent with the estimates of adults (ages 18-64) diagnosed with a psychiatric or mental disorder (Stoddard & Kraus, 2004; U.S. Department of Health and Human Services, 2000). The types of EBD vary depending on the ages sampled, and whether or not individuals were receiving services. In a study (Vander Stoep et al., 2000) of 16- to 17-year-olds, the most prevalent diagnoses were disruptive behavior disorders, substance-related disorders, anxiety disorders, and depressive disorders, respectively. Studies examining older populations (17-25) found that disruptive behavior disorders were less common than other disorders, such as depressive disorders, anxiety, substance abuse, and personality disorders (Aalto-Setala et al., 2001; Vander Stoep, Davis, & Collins, 2000).

Although approximately 6.5 million emerging adults experience emotional or behavioral difficulties (Clark & Davis, 2000), schools have been “slow to recognize the educational needs and demands that these students pose to themselves, to the major social agents in their lives (e.g., parents and teachers), and society at large” (Gresham, 2005, p.

328). Students reporting disabilities represent 9.3% of all undergraduates, or approximately 1.53 million students (Heath Resource Center, 2002). Postsecondary students with EBD are among the second largest group of students reporting disabilities, with 17.1% of this population (Heath Resource Center, 2002). Anecdotal evidence also indicates an increase in the number of students with EBD seeking and receiving services from university disability service support providers in higher education (Eudaly, 2002).

Despite the increase of individuals with EBD attending postsecondary institutions, these individuals are not only discouraged from, but are often unsuccessful in, their academic pursuits (Unger & Pardee, 2002). Failure to pursue or attain educational and vocational goals may lead to unemployment, underemployment, or underachievement (Pettella, Tarnoczy, & Geller, 1996). Although enrollment of students with disabilities in postsecondary education has increased, these students are completing their programs of study at a lower rate than are their non-disabled peers (Stodden, Whelley, Chang & Harding, 2001). Furthermore, students with psychiatric disabilities also must contend with negative attitudes and stereotypes regarding mental illness (Becker, Martin, Wajeeh, Ward, & Shern, 2002). There are multiple reasons for these failures, including lack of support from colleges and community mental health systems, cognitive skill problems, perceived stigma, lack of opportunities, and the nature of the illness itself (Guiffre, 2003; Pettella, Tarnoczy, & Gellar, 1996).

The 1990 reauthorization of the Individuals with Disabilities Education Act (IDEA) (PL 101-476, 1991) requires transitional programming and services and Section 504 of the Rehabilitation of 1973 mandates postsecondary institutions to provide

accommodations for individuals with disabilities. However, longitudinal studies also indicate individuals with emotional or behavioral difficulties “experience longer delays in obtaining employment after graduation from school, lower percentages of employment after leaving school, and lower employment rates overall,” in comparison to individuals with no disabilities or disabilities other than EBD (Jolivet et al., 2000, p. 2). These poor outcomes result “not only into untapped talent and potential and unfulfilled dreams, but severely limits America's preparation of today's youth for full participation in tomorrow's society” (National Council on Disability, 2000, p. 1). Further, postsecondary education is an important component of career development and enhancement. Indeed, according to Bellamy and Mowbray (1998), "education is a valued entity in this society, allowing many not only an opportunity to learn, but also to enjoy the benefits related to it, such as employment and status" (p. 401). Moreover, higher education is becoming increasingly integral to employability for all individuals (Mowbray, 1999).

#### Rationale and Purpose of the Study

Much has been written regarding the poor outcomes of emerging adults with disabilities, and emotional and behavioral difficulties in particular (Clark & Foster-Johnson, 1996; D'Amico & Blackorby, 1992; Davis & Vander Stoep, 1997; Jolivet et al., 2000; Leavey, 2003; Maag & Katsiyannis, 1998; Marder & D'Amico, 1992; Massey, 2004; Wagner, Cadwallar, Newman, & Marder, 2003). However, less is known about individuals who are coping with their emotional or behavioral difficulties and pursuing their desired postsecondary academic goals. Even though the number of transition-aged individuals with EBD is significant, few studies have explored the

experiences of this population engaged in educational activities. There is literature examining transitional services for individuals served in special education programs (Clark & Davis, 2000; Epstein, Kutash, & Duchnowski, 2005; Prange et al., 1992; Silver et al., 1992; Vander Stoep, 1992; Vander Stoep & Taub, 1994; Wagner et al., 2003), and supported education and supported employment programs (Bond, Drake, Mueser, & Becker, 1997; Bybee, Bellamy, & Mowbray, 2000; Pettella et al., 1996; Unger & Pardee, 2002), as well as community based programs (Bullis et al., 1994; Cheney et al., 1998). However, there is limited information regarding the personal experiences of emerging adults with EBD. There are even fewer studies examining the experiences of young adults currently pursuing their educational goals. It is also important to understand their perspective regarding what supports are needed to assist them. Supports and services for individuals with EBD must be based on the concerns and experiences of this population (MacNaughton, 1997; Morrow & Chappell, 1999).

The purpose of the study is to acquire a better understanding of the experiences of young adults diagnosed with an emotional or behavioral difficulty who are working toward their academic goals. Exploring the experiences and beliefs of these individuals may lead to more awareness of how young adults with EBD conceptualize their disability while pursuing their educational goals. Further, this study may give voice to individuals who have not had the opportunity to share their experiences and beliefs.

### Theoretical Framework

The conceptual basis for this study is the transition from adolescence to young adulthood. Tinto (1993) defined transition as “a period of passage between the old and



the new, before the full adoption of new norms and patterns of behavior, and after the onset of separation from old ones” (p. 97). Successful transition into young adulthood requires the following developmental tasks: forming independence from family of origin, achieving emotional autonomy, developing relationships outside the family, creating an adult identity, developing intimacy, accepting responsibility for decision making, pursuing education and/or vocational goals, creating a personal and choosing religious and political ideologies, and developing a sense of purpose (Holmes, 1995; Leavey, 2003; Massey, 2004; Stover & Hopkins, 1999).

The transition process is difficult for most young adults, and poses particular challenges for youth with EBD. Many of the services (e.g., child welfare, children’s mental health services, and special education) provided to young adults with emotional and behavioral difficulties end at age 18 or high school graduation (Vander Stoep, 1997). Furthermore, many of these service systems lack an adult counterpart, or eligibility criteria may change, leaving individuals with EBD without appropriate supports when they are needed the most (Vander Stoep, 1997; 1994). In addition to these challenges, there are many factors that affect the transition process, including self-determination, identity, resiliency, and stigma.

In order to understand the experiences of young adults with emotional and behavioral difficulties, it is critical to consider how these individuals successfully transition into adult roles. It is also important to examine the supports and barriers that young adults identify as impacting their transition experience.

## Questions

The following questions will be addressed in this study:

1. How do selected emerging adults perceive and describe the experience of being diagnosed and living with an emotional or behavioral difficulty?
2. How do selected emerging adults with emotional or behavioral difficulties perceive and describe the impact of their disability on their transition experience and ability to reach their future goals?
3. How do selected emerging adults with emotional or behavioral difficulties perceive and describe the role of supports that contribute, and those that could contribute, to achieving their desired vocational and educational goals?

## Definitions

### *ADA Definition of Disability*

The American Disabilities Act (1990) (PL 101-336) defines disability as: "(1) a physical or mental impairment that substantially limits one or more major life activities of an individual; (2) a record of such impairment; or (3) being regarded as having such impairment." A mental impairment is defined by the ADA as "any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities" (American with Disabilities Act, 1990). While there are numerous definitions for psychiatric disabilities, in order for students to qualify for accommodations at postsecondary institutions, they must meet the requirements of this definition.

### *Emerging Adulthood*

Arnett (2006) defines emerging adulthood as a distinct period in the life course of an individual, occurring during the years roughly between the years of 18 and 25 (p. 4).

### *Emerging Adults*

For the purpose of this study, emerging adults are defined as individuals roughly between the ages of 18 and 25 (Arnett, 2006). Although individuals are generally classified as young adults from ages 16 to 25 (Davis & Vander Stoep, 1997), 18 was selected as the minimum age because the study will examine postsecondary experiences. The terms emerging adults and young adults will be used interchangeably in this study.

### *Emotional and Behavioral Difficulties*

For the purposes of this study, the term “emotional and behavioral difficulties” refers to “a health condition characterized by alteration in thinking, mood, or behavior, or a combination of all three linked to distress and/or impaired functioning in a person” (Mental Health: A Report of the Surgeon General, 1999). Specifically, individuals who have been identified with the following Axis-I disorders, as classified in the current Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), will be included in the study: schizophrenia, mood disorders, including major depressive disorder and bipolar disorders, and anxiety disorders (American Psychiatric Association, 2000). The term “emotional and behavioral difficulties” will be utilized throughout the study, unless another expression appears within a quoted text or is used within a specific context or framework.

### *Anxiety Disorders*

Anxiety disorders are the most common disability and include panic disorders, phobias, generalized anxiety disorders, and obsessive-compulsive disorders (Charney, 2005).

### *Mood Disorders*

Mood disorders are syndromes that consist of a cluster of symptoms and signs that represent a significant departure from a person's typical functioning. These symptoms and signs are sustained over a period of weeks to months and tend to recur, either a cyclical or periodic function (Akiskai, 2005, p. 1562)

*Bipolar Disorders.* There are four types of bipolar disorder, Bipolar I, Bipolar II, Cyclothymia and Bipolar NOS (Not Otherwise Specified). Bipolar disorder is characterized by recurrent episodes of significant disturbances in mood. Most individuals experience a depressive phase and either mania, a distinct period of an expansive, irritable, or elevated mood state, hypomania, a less extreme state of mania, or a mixed state, in which symptoms of mania and depression occur at the same time (Akiskai, 2005; American Psychiatric Association, 2000).

*Major Depressive Disorder.* A major depressive episode is characterized by a significantly diminished interest or pleasure in all or most activities, nearly everyday, a depressed mood most of the day, nearly every day, sleep disturbances, marked increase or decrease in weight, low energy or fatigue, agitation or retardation, recurrent thoughts of death or suicidal ideation (American Psychiatric Association, 2000).

### *Schizophrenia*

Schizophrenia is a disturbance that lasts at least six months and includes at least one month of active symptoms, which are hallucinations, delusions, withdrawal, incoherent speech, and impaired reasoning (American Psychiatric Association, 2000). Schizophrenia is marked by disruptions in thinking, disorganized speech, and/or grossly disorganized or catatonic behavior (American Psychiatric Association, 2000).

### *Serious Emotional Disturbance*

A serious emotional disturbance is marked by the exhibition of behavior disorders over a long period of time, which adversely affects educational performance. These include an inability to learn that cannot be explained by intellectual, sensory, or health factors; an inability to build or maintain satisfactory interpersonal relationships with peers and teachers; inappropriate types of behaviors or feelings under normal circumstances; a general pervasive mood of unhappiness or depression; and/or a tendency to develop physical symptoms or fears associated with personal or school problems. The term does not include children who are identified as socially maladjusted, unless it is determined that they have a serious emotional disturbance (Individuals with Disabilities Education Act, 1997) (PL 101-476).

### *Transition Services*

IDEA mandates transition services for individuals with disabilities ages 14 to 21. Transition services IDEA (PL 108-446, 2004) defines transition services as:

A coordinated set of activities for a child with a disability that:

- a) Is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education; vocational education; integrated employment (including supported employment); continuing and adult education; adult services; independent living or community participation; and [602(34)(A)]
- b) Is based on the individual child's needs, taking into account the child's strengths, preferences and interests. [602(34) (B)] (Individuals with Disabilities Education Act, 2004)

## CHAPTER TWO

### REVIEW OF THE LITERATURE

Transition from adolescence to adulthood is a challenging and complex process for all individuals. Emerging adults with emotional and behavioral difficulties (EBD) encounter even more obstacles in their efforts to complete developmental tasks required during the transition process, such as completing school, finding fulfilling work, developing a network of friends, and becoming an active member in their community. Research regarding the outcomes for this group indicates that individuals with EBD have less favorable outcomes than their peers, despite legislation mandating supports and services for all individuals with disabilities. This chapter will provide an overview of the literature regarding the transition experience for young adults with EBD. Specifically, this discussion will define emerging adulthood; explore the nature and challenges of transitioning from adulthood, particularly for individuals with EBD; examine previous studies focused on the outcomes of this population; and, provide an overview of current supports and services for young adults with emotional and behavioral difficulties. An overview of phenomenology, as a philosophical perspective and a research method, will also be provided. Finally, the relevant gaps in the literature will be reviewed.

#### Emerging Adulthood

According to Arnett (2006), the years roughly between 18 and 25 represent a distinct period in the life course of an individual. He designates this period as emerging

adulthood, and distinguishes it from adolescence and young adulthood, which he argues extends to age 40. This life stage includes the transition from adolescence to adulthood, and is characterized by new responsibilities, significant events, and changes that influence the future of young adults. Whereas Erikson (1950) proposed that identity development occurs during adolescence and may extend into young adulthood, Arnett (2006) asserted that identity explorations take place during emerging adulthood, and that “resolution of identity may be postponed as a function of emerging adulthood explorations” (Tanner, 2006, p. 23). Blos (1962) also identified a distinct period between adolescence and young adulthood, which he termed post-adolescence, and contended that identity is consolidated during this life stage (Tanner, 2006). Kroger (2007) designated this life stage, occurring between the ages of 18-22, as late adolescence. It is during this time, according to Kroger, that individuals explore friendships and intimate relations, their sexuality and gender roles, and their values. Although it is possible to identify and describe common themes of emerging adulthood, it is important to note that this is a diverse population and is “in part defined by its heterogeneity, that is, it is perhaps the period of life in which variance is greatest, in many aspects of development” (Arnett, 2006, p. 15).

#### *Features of Emerging Adulthood*

Arnett (2006) identifies five features of emerging adulthood, which include the Age of Identity Explorations, The Age of Instability, the Self Focused Age, The Age of Feeling In-Between, and the Age of Possibilities (p. 7-14). The Age of Identity Explorations involves exploring possibilities and choices in a variety of domains, such as



work, love, relationships, and values, which help emerging adults determine what they desire from life and who they are. It is during this stage that individuals clarify their identity.

The Age of Instability refers to the dynamic nature of emerging adulthood. During this life stage, most individuals change direction in education, employment, and/or intimate relationships. Furthermore, residential changes peak during this period; individuals may move away from and then return to their parents' home, or may live with roommates or a partner, and then move out when life circumstances change or a relationship terminates (Arnett, 2006). Emerging adulthood is a Self-Focused Age because it is a time in which young adults have fewer social obligations, commitments to others, and duties, as compared to other life stages. Although this stage is marked by freedom and fewer responsibilities, this is the period in which emerging adults are attaining self-sufficiency and autonomy (Arnett, 2006; 2000).

Many individuals in their late teens and early twenties often describe themselves as feeling “in-between”; they are no longer adolescents, but not quite adults (Arnett, 2006, p. 11). Hence, The Age of Feeling In-Between is a feature of emerging adulthood. Individuals identify three important criteria for adulthood: accepting personal responsibility, making independent decisions, and becoming financially independent (Arnett, 2006). These criteria differ from transitional events such as getting married, completing education, and entering the workforce. Indeed, these criteria are more gradual and harder to identify. Finally, emerging adulthood is The Age of Possibilities. This is a time of high hopes and optimism for the future. A national survey of 18- to 24-year old

Americans reported that they were sure they would achieve their goals in life (Hornblower, 1997). Emerging adulthood is also the age of possibility for those who have experienced difficult conditions earlier in life. They now have the opportunity to move away from home and direct their lives in a positive direction (Arnett, 2006). For most young persons, emerging adulthood represents an opportunity for transformation, independence, and a chance to establish their own identity.

### *Educational and Employment Characteristics of Emerging Adults*

As previously stated, emerging adulthood is marked by independence and identity exploration as well as its heterogeneity and diversity. There are many different options and paths for young adults, including full-time and part-time enrollment in a postsecondary institution, enrollment in 2- or 4-year colleges, full-time employment, military enlistment, parenting, or unemployment (Hamilton & Hamilton, 2006).

Entering college is a common choice for young adults, 45% of individuals aged 18- to 24-year-olds were enrolled in college in 1999 (Barton, 2002, pp. 7-8); this number increased to 61.7% by 2001 (U.S. Department of Labor, Bureau of Labor Statistics, 2002). Young women enrolled at a higher rate than their male peers (63.6% to 59.8%), and white youth enrolled at a higher rate (63.1%) than Black youth and Hispanic youth (51.5%) (U.S. Department of Education, National Center for Education Statistics, 2002, p. 73). Although college enrollment has increased, the percentage of students graduating from 4-year colleges within 5 years of entry has decreased from 58% in 1983 to 51% in 2001 (Barton, 2002; Hamilton & Hamilton, 2006, p. 12). Only 29% of 25 to 29 year olds had attained a bachelor's degree in 2001 (U.S. Department of Education, 2002, p. 89).

The majority of students enrolled in postsecondary institutions for credit (60%) attend 2-year institutions, while 30% of all postsecondary students are enrolled in vocational programs (Bailey et al., 2003; Hamilton & Hamilton, 2006).

The majority (80.6%) of high school graduates who did not attend a postsecondary institution in 2001 were working or looking for work (U.S. Department of Labor, 2002). However, unemployment rates are very high for young adults, but this may be due to frequent job changes, and the prevalence of part-time employment combined with enrollment in education (Hamilton & Hamilton, 2006, p. 261). Indeed, in 2001, 43% of full-time first-year college students were employed or looking for work and 71.6% of students enrolled in 2-year colleges were in the labor force (U.S. Department of Labor, 2002).

The decisions of emerging adults have a significant impact on their career paths and later achievements. Not surprisingly, attaining postsecondary education is a significant factor. Academic achievement usually results in greater employment opportunities and higher income, even among students who do not earn a college degree (Hamilton & Hamilton, 2006, p. 273). Two year degrees, vocational training, and occupational certification can also lead to successful careers. Career directedness is another important factor to successful outcomes, even when career paths change. Students without career goals during high school often have to take remedial courses or have difficulty establishing a productive career (Hamilton & Hamilton, 2006). Furthermore, academic achievement and career directedness are related; those who have

a career direction are more likely to succeed in school than those without a sense of a career path.

### *Emerging Adults with Emotional and Behavioral Disorders*

Emerging adulthood is a high-risk period for the onset of emotional and behavioral difficulties; major depressive disorders, bipolar disorders, borderline personality disorders and schizophrenia usually manifest between the ages of 17 to 25 (Ackerman, 2006; Cicchetti & Rogosch, 2002; Schulenberg & Zarrett, 2006; Trull, 2001). Both early-onset and adult-onset of psychiatric symptoms can lead to lost opportunities in admission or success in postsecondary institutions and the risk of academic failure and leaving college (Ackerman, 2006).

Prevalence rates of individuals with EBD vary in the literature, due to inconsistency in how disabilities are defined and measured. However, most estimates of young adults (ages 16-25) with a mental or psychiatric disorder range from 18% to 23% (Aalto-Setala et al., 2001; Cohen et al., 1996; Friedman, 1996). This number is consistent with the estimates of adults (ages 18-64) diagnosed with a psychiatric or mental disorder (Stoddard & Kraus, 2004; U.S. Department of Health and Human Services, 2000). Studies examining transition-aged individuals (17-25) found that disruptive behavior disorders were less common than other disorders, such as depressive disorders, anxiety, substance abuse, and personality disorders (Aalto-Setala et al., 2001).

Unfortunately, only a small percentage of 18- to 25-year-olds receive mental health treatment or services (Vander Stoep et al., 2000). Three longitudinal studies, the National Longitudinal Transition Study (NLTS), the National Adolescent and Child

Transition Study (NACTS), and the McGraw Study<sup>2</sup> found that only a small proportion of participants received mental health care from specialists (Clark & Davis, 2000, p. 9). Longitudinal studies also indicate individuals with emotional or behavioral difficulties “experience longer delays in obtaining employment after graduation from school, lower percentages of employment after leaving school, and lower employment rates overall,” in comparison to individuals with no disabilities or disabilities other than EBD (Jolivet et al., 2000, p. 2). These poor outcomes result “not only into untapped talent and potential and unfulfilled dreams, but severely limits America's preparation of today's youth for full participation in tomorrow's society” (National Council on Disability, 2000, p. 1).<sup>3</sup>

### Transition

As indicated above, transitioning from adolescence into adulthood is a significant, but challenging, aspect of emerging adulthood. Indeed, more social changes occur during this stage than any other period of life (Shanahan, 2000). In American culture, the transition process involves developmental tasks such as completing school, developing a network of friends, creating an adult identity, contributing to the maintenance and support of a household, finding fulfilling work, and participating as a member in a community (Clark & Davis, 2000; Leavey, 2003). According to Arnett (2000), 95% of 12- to 17-year-olds are students and live with one or more parent, 98% are unmarried and less than 10% are parents. By the age of 30, 90% are no longer enrolled in school, 75% are married, and 75% are parents (Arnett, 2000).

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<sup>2</sup> The NLTS and NACTS will be described in greater detail later in the chapter.

<sup>3</sup> Further discussion of outcomes for individuals with EBD will be presented later in this chapter.

The transition process is a difficult experience for the majority of young adults, who must make life-changing decisions just as institutional structure decreases and personal responsibility increases (Schulenberg & Zarrett, 2006; Shanahan, 2000). Transition is even more complicated for young adults with EBD for various reasons, including personal challenges (e.g. impairments in skills needed for successful transition), and difficulties related to formal and informal support systems (Cheney et al., 1998; Osgood, Foster, Flanagan, & Ruth, 2005; Schoeni & Ross, 2005). There are several factors, both positive and negative, that influence successful transition, including self-determination, resilience, and stigma.

### *Developmental Tasks*

Developmental transition refers to the natural maturation process, starting in late adolescence and continuing through early adulthood. This process is mediated by cultural expectations and is unique to each individual (Vander Stoep et al., 2000). However, emerging adults are expected to complete certain developmental tasks in order to successfully transition into young adulthood. Whereas there are many pathways emerging adults can choose, there are key domains to the transition process, including entering adult roles, establishing satisfying relationships, education and training, and employment (Holmes, 1995; Leavey, 2003; Massey, 2004; Osgood et al., 2005; Stover & Hopkins, 1999). Because transition is a significant aspect of emerging adulthood, many of these developmental tasks overlap with the characteristics of this life stage.

### *Entering Adult Roles*

Entering adult roles includes such developmental tasks as leaving the home of parents and guardians and establishing a household. This process often involves numerous residential changes; many young adults initially live in institutional settings, such as college dormitories, or temporarily live with roommates or romantic partners before establishing a more permanent household (Leavey, 2003; Osgood, et al., 2005; Werner, 2001). Developing stable romantic partnerships, such as steady dating, cohabitation, or marriage is another important aspect of entering adult roles (Osgood et al., 2005; Werner, 2001). This process includes developing a sex role identity and sexuality, exploring intimacy, and emotional regulation (Hameister, 1984; Schulenberg & Zarrett, 2006; Werner 2001). For many emerging adults, parenthood is another significant adult role. Entering adult roles also requires an individual to become self-reliant and independent.

### *Establishing Satisfying Relationships*

In addition to establishing a stable romantic partnership, developing and maintaining other personal relationships and friendships is an important part of the transition process (Hameister, 1984; Werner, 2001). Important aspects of developing a personal network of friends is formulating a philosophy of life and consolidating a sense of identity (Chickering & Reisser, 1993; Werner, 2001). Intimate relationships and friendships may change or terminate as one establishes who they are and what they want out of life.

### *Education and Training*

Education and training is another critical part of transition into adult roles. There are many different educational pathways young adults may take, including entering a 4-year or 2-year educational institution, earning different levels of degrees (e.g., high school, graduate equivalency, and college degrees), or vocational training. Academic achievement usually results in better opportunities and prospects in employment. For example, individuals who earn a bachelors degree, or higher, usually experience greater occupational income and status than peers who do not attain higher education (Chen & Kaplan, 2003; Kerckhoff, Raudenbush, & Glennie, 2001). However, attainment of 2-year degrees, vocational training, and occupational certification can also lead to successful careers (Hamilton & Hamilton, 2006, p. 273; Osgood et al., 2005).

### *Employment*

Employment is another key feature of becoming an adult, with entry into full-time employment as the typical marker (Osgood et al., 2005). Career directedness even, when career paths change, is a key component to successful employment. A sense of career direction often leads to higher academic achievement, which in turn provides greater opportunities for successful and satisfying employment.

### *Challenges to the Transition Process*

As individuals transition into adulthood in the 21<sup>st</sup> century, they face many challenges to achieving their goals. Changes in American society, including economic fluctuations, technology, changes in demographics (Levine & Wagner, 2005, p. 225), an increase in marital age, and lack of a clear sequence of major transitions into adulthood



have made the transition process less orderly and more difficult (Osgood et al., 2005, p. 9). Furthermore, the rapid decline in institutional structure and familial support (Hurrelmann, 1990; Schulenberg & Zarrett, 2006) requires emerging adults to rely on their own sense of agency and resources (Kroger, 2007, p.4). Young adults face personal challenges as well, such as a feeling of discontinuity as they transition into adult roles, or developmental mismatches between employment or educational desires and their personal abilities or opportunities (Osgood et al., 2005; Schulenberg, O'Malley, Bachman, & Johnston, 2005). Furthermore, emerging adults can become disappointed by mistakes, lack of opportunities, or a repetition of poor choices. Some youth experience difficulty establishing intimacy and therefore may feel isolated or lonely during the transition process (Holmes, 1995).

#### *Challenges for Individuals with Emotional and Behavioral Difficulties*

For emerging adults with emotional and behavioral difficulties, the transition from adolescence to adulthood is even more challenging (Osgood et al., 2005; Vander Stoep et al., 2000). Individuals with EBD may encounter personal challenges, such as delays in their ability to develop intimate relationships, establish a sense of identity, enter the workforce, and achieve independence from their family (McGorry et al., 1996; Leavey, 2003). In addition to these personal challenges, young adults with EBD must also contend with a loss, or lack of, institutional and familial supports. Further, individuals attending postsecondary institutions face numerous challenges as they pursue their goals.

### *Personal Challenges*

Young adults with EBD must deal with many personal challenges as they negotiate the transition process. Disruption of their education may result in cognitive delays, which negatively impact social functioning and educational or vocational achievement (Davis & Vander Stoep, 1997; Vander Stoep, 1997). Often, individuals experience onset of emotional and behavioral difficulties during high school, and often fall behind their peers (Leavey, 2003). In addition to cognitive delays, emerging adults with EBD may also have delays in social and moral development, resulting in poor social problem solving skills, immaturity, less social attachment, and increased conflicts with friends (Claes, 1994; Matthys, Walterbos, & Van Engeland, 1995; Vander Stoep, 1997). Further, many young adults in vulnerable populations, including individuals with EBD, have trouble avoiding problematic behavior, such substance abuse or legal trouble (Osgood et al., 2005).

### *Challenges Regarding Services and Support Systems*

*Institutional supports.* Institutional transition occurs when an individual reaches a certain age and involves changes in legal or bureaucratic status (Mallory, 1995; Vander Stoep, et al., 1997). In contrast to the gradual biological and psychological changes that occur during developmental transition, the changes involved with institutional transition are often abrupt and arbitrary (Vander Stoep, Davis & Collins, 2000). Many of the services (e.g., child welfare, children's mental health services, and special education) provided to young adults with emotional and behavioral difficulties end at age 18, or high school graduation (Vander Stoep, 1997). Furthermore, many of these service systems

lack an adult counterpart, or eligibility criteria may change, leaving individuals with EBD without appropriate supports when they are needed the most. (Levine & Wagner, 2005; Lyons & Melton, 2005; Osgood et al., 2005; Vander Stoep, 1997; 1994; Vander Stoep et al., 2000). Individuals who do receive mental health services encounter a fragmented and complex system, including both private and public service sectors (Gralinski-Bakker, Hauser, Billings, & Allen, 2005). These multiple providers, such as social security, welfare, specialty mental health services, and other human service systems have different eligibility requirements, making the process more complex (Gralinski-Bakker et al., 2005; Grisso, 2004).

*Familial supports.* The majority of young adults without disabilities rely heavily on their family as they transition from adolescence to adulthood. Families can provide both financial and emotional assistance. For examples, parents and guardians often pay for postsecondary education, give their children money to help with expenses, or continue to provide food and shelter (Osgood et al., 2005). Emotional support is also integral to successful transition. Research has found that positive parental support is associated with higher perceptions of academic competences and higher scholastic achievement (Cutrona, Cole, Colangelo, Assouline, & Russell, 1994; Osgood et al., 2005). Young adults with EBD often have strained or limited relationships with their families and their transition efforts may be hindered by unreliable or non-existent familial support (Osgood et al., 2005). Furthermore, some families of young adults with EBD may be willing, but unable, to provide the necessary financial or emotional support needed for successful transition.

*Challenges for Postsecondary Students with Emotional and Behavioral Difficulties*

According to the President's Commission on Excellence in Special Education (U.S. Department of Education, 2002), "students with disabilities who elect to continue their education at the postsecondary level ... face significant barriers to achieving their goals" (p. 48). Bento (1996) conducted interviews at a mid-size state university regarding barriers to providing and receiving accommodations for students with learning disabilities. She identified three key categories, including informational, ethical, and attitudinal barriers. Informational barriers refer to limited knowledge of relevant legislation and inadequate understanding of the nature of disabilities; ethical barriers denote concerns by faculty members and other students that accommodations are unfair to other students; and, attitudinal barriers involve the effects of ambivalent beliefs on faculty behaviors regarding students with disabilities (Bento, 1996). These findings are consistent with other studies that have identified resistance by faculty members, misinformation, and lack of resources as being common barriers to accommodating students with disabilities (Greenbaum et al., 1995; Thomas, 2000). Deshler, Ellis, and Lenz (1996) reported that the negative attitudes of faculty are cited as a central reason students with disabilities fail at postsecondary institutions. These attitudes may be explained by the mission of universities and colleges, where the "priorities for faculty in higher education center on scholarship and research, not the provision of social services, which has become so integral to the mission of elementary and secondary schools" (Beilke & Yssel, 1999, p. 368). Other barriers to serving students with disabilities include inadequate staff and funding for student disability service offices, the absence of

comprehensive support programs, and students' lack of preparedness for college (Bento, 1996; Deshler et al., 1996).

Students with EBD must contend with these challenges, particularly stigma and misinformation regarding mental illness. Blacklock et al. (2003) noted five major barriers impacting delivery of services and education experiences of students with psychiatric disabilities: stereotypes and stigma, access to information and services, the complex nature of EBD, access to resources, and organization and institutional barriers (Blacklock et al., 2003; Sharpe et al., 2004). Of these barriers, stigma and negative stereotypes are perhaps the most frequently cited (Becker et al., 2002; Eudaly, 2002; Sharpe et al., 2004; Sharpe & Johnson, 2001). Many institutions and individuals operate based on "old knowledge" regarding EBD, and are not aware of effective psychosocial and medical interventions for schizophrenia, depression, and bipolar, that help reduce and lessen the severity of "psychotic episodes" (Unger, 1994). In a survey of faculty and student beliefs regarding serious psychiatric disabilities, Becker et al. (2002) found "a troubling minority" (13%) of faculty felt students they viewed as having an EBD would cause them to feel unsafe (p. 364). Moreover, approximately one-half of the faculty stated "they would not feel comfortable" working with a student "exhibiting symptoms of a mental illness" and 10% of the faculty reported they would "be very uncomfortable with such interaction" (Becker et. al., 2002, p. 365). Not surprisingly, individuals with EBD are all too aware of negative attitudes and beliefs, and may be less likely to seek or obtain services (Frado, 1993; Marrone, 2004). Weiner (1999) reported that students often did not want to disclose their illnesses because of fear of being labeled or negatively

perceived. However, seeking and obtaining services is often integral to success. Weiner (1999) also found that medical concerns such as anxiety, difficulties with motivation, concentration, and short-term memory often prevented participation or success.

### *Factors Influencing Successful Transition*

There are many factors that influence transition from adolescence to adulthood, including self-determination, resilience and stigma. Self-determination and resilience can have a positive impact on the transition process and can be enhanced by education and support. In contrast, stigma often has a negative effect on transition.

### *Self-Determination*

Self-determination is a theoretical construct that involves personal abilities and attitudes that empower an individual to identify and pursue goals (Powers et al., 1996; Wehmeyer, 1996). According to Deci and Ryan (1985), self-determination is “the capacity to choose and to have those choices be the determinants of one’s actions” (p. 38). Self-determined individuals participate in decision making, identify goals and the requisites for achieving those goals, participate in selecting courses and career planning, and advocate for their desires and needs (Levine & Wagner, 2005; Wehmeyer, 1996).

Both the Individuals with Disabilities Act (IDEA) (PL-101-476, 1990) and the 1992 Amendments to the 1973 Rehabilitation Act (PL 102-569) recognize self-determination as significant outcome for youth with disabilities (Wehmeyer, 1996). Halloran (1993) goes even further, designating self-determination as “the ultimate goal of education” (p. 214). Self-determination is clearly an integral component to successful

transitions because it allows young adults to identify and work towards their personal goals.

### *Resilience*

Resilience refers to the dynamic process of achieving positive adaptation despite adversity or risk (Luthar, Cicchetti, & Becker, 2000; Vanderbilt-Adriance, 2006). The processes associated with resilience include a close and supportive relationship with one parent or adult outside the family, positive characteristics of the family and community, pro-social friends, safe neighborhoods, and effective schools (Masten, 1994; Masten, Best, & Garmezy, 1990). Resilience is an important factor with regards to emerging adulthood and transition because it is during this period that important changes in personal responsibility, living arrangements and functional capacity occur (Masten, Obradovic, & Burt, 2006). As previously discussed, some young adults, particularly vulnerable populations, may have significant problems entering adult roles and achieving critical developmental tasks.

Project Competence, a longitudinal study of a school based cohort of children followed through adulthood, found that:

- Achievements in the developmental tasks of adolescence provide a strong foundation for successful transitions to adulthood;
- Resilience already evident in adolescence holds up well during emerging adulthood;
- Resilience can emerge during and following emerging adulthood;

- Conjunctions of individual motivation for change, growth in thinking and planning capacity, adult support, and contextual opportunities may create the conditions for changing the life course; and,
- Emerging adulthood may provide a unique window of opportunity for strategic intervention to promote positive change. (Masten et al., 2006, p. 175).

Resilience is of particular importance to vulnerable populations, such as young adults with EBD, because the study of resilience attempts to explore how some individuals succeed despite difficult or adverse circumstances (Hauser, 1999). When considering resilience, it is necessary to consider the strengths and deficits of individuals, as well as protective and risk factors. There are multiple sources for protective factors, such as personality traits and skills, involvements in community groups, churches or clubs, and positive relationships (Masten et al., 2006).

### *Stigma*

According to Crocker, Major, and Steel (1998), “a person who is stigmatized is a person whose social identity, or membership in some category, calls into question his or her full humanity—the person is devalued, spoiled, or flawed in the eyes of others” (p. 504). Goffman (1963) defines stigma as any “persistent trait of an individual or group which evokes negative or punitive responses” (p. 14). It is a powerful social construction that is characterized by the recognition of difference based on some distinguishing trait and a devaluation of the person (Dovidio, Major, & Crocker, 2000).



Stigma is a pervasive concept in the literature regarding individuals with emotional or behavioral difficulties, and many researchers have studied the effects of stigma on these emerging adults as they transition from adolescence to adulthood. For example, it is documented that educational opportunities have been often been denied to individuals with EBD because of negative attitudes and beliefs regarding their disability (Unger, 1994; Weiner, 1999). Research has also demonstrated that stigma complicates the transition process because it may reduce choices in fundamental life domains (Osgood et al., 2005, p. 216).

Furthermore, two-thirds of all individuals with EBD do not seek treatment due to the stigma associated with mental health problems (Bush, 2002; Mechanic, 2002; World Health Organization, 2002). As previously stated, Weiner (1999) reports that college students often did not want to disclose their illness because of fear of being labeled or negatively perceived. However, seeking and obtaining services is often integral to educational and vocational success. Conversely, failure to seek treatment or assistance may lead to poor educational outcomes.

#### Outcomes for Emerging Adults with Emotional and Behavioral Disorders

When considering the transition from adolescence into adulthood, it is necessary to consider the outcomes of young adults with emotional and behavioral difficulties. As previously discussed, fragmentation of mental health, education and rehabilitation services have led to poor outcomes for emerging adults with EBD. Despite transitional programming and services, as required by the 1990 reauthorization of IDEA (PL 101-476), longitudinal studies indicate individuals with emotional or behavioral difficulties

“experience longer delays in obtaining employment after graduation from school, lower percentages of employment after leaving school, and lower employment rates overall,” in comparison to individuals with no disabilities or disabilities other than EBD (Jolivette et al., 2000). Further, this population has the lowest outcomes regarding independent living, incarceration, and later employment (Davis & Vander Stoep, 1995; Marder & D'Amico, 1992).

The National Longitudinal Studies (NLST and NLST2), and the National Adolescent and Childhood Transition Study (NACTS) followed the progress of children and youth involved in special educational or mental health systems. The Young Adults in the Community Study (YAICS) represents one of the few longitudinal studies focusing on young adults who were not in special educational programs or receiving residential treatment services. This research is important because many young adults with EBD do not seek treatment and/or have not been identified as needing special education services.

*National Longitudinal Transition Study (NLTS) and  
National Longitudinal Transition Study-2 (NLTS2)*

The National Longitudinal Transition Study, which began in 1987 and ended in 1993, followed more than 8,000 students identified as having a disability, including 800 students identified as having an emotional disorder (ED)<sup>4</sup> (Wagner, 1995; Wagner & Blackorby, 1996). The nationally representative sample of students ages 13 to 21 was selected from more than 300 school districts nationwide (Wagner, 1995). Data were

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<sup>4</sup> The terms SED and ED are used interchangeably in the majority of the longitudinal studies. The federal definition of SED is provided in Chapter One.

collected using telephone interviews with parents and the students themselves, school records, and surveys completed by principals and teachers (Wagner & Blackorby, 1996). The NLTS sought to describe the characteristics and experiences of secondary school students in special education, as well as their postsecondary experiences. They also measured post-school outcomes of youth with disabilities, considering education, social, employment, and residential domains.

Across most measures, youth with ED experienced poorer outcomes than their peers with and without disabilities. Results from the NLTS indicated that 47% of young adults with ED held competitive employment three to five years after completing their secondary school experience, compared to 57% of youth with disabilities that held competitively employment, and compared to 69% of the general population (Levine & Wagner, 2005). Perhaps more distressing are outcomes regarding residency; young adults identified as SED were more likely than youth with other disabilities to be living in a halfway house, drug treatment center, on the street, or in a correctional facility (10% versus 4%) (Wagner, 1995).

Moreover, youth without disabilities attended postsecondary schools at a much higher rate (68.3%) than youth with ED (25.6%) (Wagner & Blackorby, 1996). Young adults with ED also experienced poorer outcomes socially. Three to five years after high school, they were less likely to be living with a romantic partner or be married than their non-disabled peers. Although young women with SED were less likely to be married (27% versus 38%), they were more likely to have children than their peers in the general population (48% versus 28%) (Wagner, 1995).

The National Longitudinal Transition Study 2 (NLTS2), sharing the same purpose and using similar methodology to the original NLTS (Wagner & Blackorby, 1996), will collect data for 10 years, from 2001-2011. The study will follow 11,000 young people with disabilities, aged 13 through 16, who received special education services in seventh grade or higher during the 2000-01 school year (Wagner, Newman, Cameto, & Levine, 2005). Because this is an ongoing study, data are collected in waves. The report discussed here (Wagner et al., 2005) focused on youth with disabilities out of secondary school, and of ages 15 through 19. Telephone interviews were conducted with parents and the young adults, when possible, in both 2001 and 2003. Although the study examines the experiences in employment, independence, postsecondary education, and social domains, as well as the individual and household characteristics of all youth with disabilities participating in the study, this discussion will focus on the experiences and characteristics of individuals with emotional disturbances (ED).

This study yielded distressing results regarding the post-school of young adults with ED with respect to several domains, including drop-out rates, residential settings, parenting, employment and community engagement, postsecondary education, and interactions with judicial system. Specifically, 44% of this population drop-out of school without finishing, a higher rate than their peers without disabilities (Wagner et al., 2005). They are also the largest group to not live with parents (35%); alternate living arrangements include mental health or criminal justice placements, foster care, or living on the street (Wagner et al., 2005). Young adults with ED also experience the highest rate of having had or fathering a child (11%). With regards to community involvement, about

33% of young adults with ED are not engaged in their community, either through employment, volunteer activities, community groups, or voting. Only about 30% of this population was currently employed, and only 20% have participated in any kind of postsecondary education (Wagner et al., 2005). Clearly, poor employment history and lack of education will limit future opportunities for youth with ED.

*National Adolescent and Childhood Transition Study (NACTS)*

The purpose of the National Adolescent and Childhood Transition Study (NACTS) was to collect descriptive data on children and youth with ED (Greenbaum & Dedrick, 1996). The longitudinal study, which took place during the same time period as NLTS, conducted an analysis of the outcomes for children and youth identified as ED by either the mental health system or the school system. Eight hundred and twelve children, aged 9 through 17, were examined over a seven-year period (Wagner, et al., 2005). Data were collected annually, using multiple sources such as personal interviews with children, teachers, parents and caregivers, as well as examination of clinical and educational records (Bisset, 2004). Students were selected from six different states, including Alabama, Mississippi, Florida, Colorado, New Jersey and Wisconsin; 121 sites agreed to participate in the study, including 27 mental health centers and 94 special education sites (Bisset, 2004; Greenbaum & Dedrick 1999).

The data revealed similar outcomes to the NLTS study (Wagner et al., 1995). The results indicated that at the beginning of the study, the youth experienced significant problems in many areas of their lives (Bisset, 2004). Despite improvements in emotional functioning overtime, overall academic outcomes were poor and students with ED

displayed a pattern of underachievement (Greenbaum & Dedrick, 1999). The data revealed a high comorbidity between ED and substance abuse disorders, as well as a high rate of involvement with law enforcement (Wagner et al., 2003). In addition, 40% of young adults with ED did not complete their secondary education, either through a high school diploma or GED (Wagner et al., 2003). These results, in conjunction with the results of NLTS and NLTS2 confirm the negative experiences and outcomes for youth with emotional and behavioral difficulties.

*The Young Adults in the Community Study (YAICS)*

The Young Adults in the Community Study (YAICS) is one of the few community based studies of transition, and was a part of the Children in the Community Study (CICS) (Vander Stoep, et al., 2000). The CICS followed the course of a cohort of children who represented the general U.S. population in residence, family structure and socioeconomic status (Bisset, 2004; Vander Stoep et al., 2000). One thousand, one hundred and seventy-four youth, from two communities in upstate New York, were randomly selected to participate in the CICS; of those, 976 households completed interviews. The longitudinal study, spanning from 1975 to 1986, consisted of three waves.

One hundred and eighty-one young adults were selected from the CICS to participate in the YAICS, which compared the outcomes of 33 young adults with an ED to 148 youth without an emotional disorder. In order to qualify, young adults had to be identified as having an Axis I diagnosis of anxiety, depressive, disruptive, or substance abuse disorder, based on The Diagnostic and Statistical Manual of Mental Disorders,

Third Edition (1980). Further, these participants were not 18 at the time of the wave 2 interview in 1983, but were 18 or older when they participated in the wave 3 interview in 1985-86 (Vander Stoep et al., 2000). This decision was made in order to capture the participants' experiences as they "crossed the threshold" into young adulthood (p. 353).

The study examined outcome measures across five domains, including secondary school completion, gainful activity (e.g., engagement in postsecondary employment or education), criminal involvement, sexual activity, and social support (Vander Stoep et al., 2000). Thirty-nine percent of young adults with an ED either did not complete, or were not on course to completing, high school, and they were three and a half times less likely to be engaged in gainful activity, such as employment or enrolled in an educational program (Bisset, 2004; Vander Stoep et al., 2000). Almost 25% of young adults with an ED were involved with law enforcement within 2 years before the wave 3 interview (Vander Stoep et al., 2000). Although there was not a significant difference in sexual activity between the two groups, almost 30% of youth with an ED reported either having been pregnant or having gotten someone else pregnant (p. 357). Youths with ED lived alone at a higher rate than their non-disabled peers, although no measure of social support indicated any statistically significant difference (p. 357). Although this is a relatively small study, the findings are consistent with the previous longitudinal studies discussed above.

## Current Supports and Services for Emerging Adults with Emotional and Behavioral Difficulties

Despite, or perhaps due to, discouraging outcomes for youth with emotional and behavioral difficulties, there is considerable legislation and research on supports and services for this population. Federal laws, such as the Rehabilitation Act (PL 93-112, 1973), the Individuals with Disabilities Education Act (IDEA) (PL 101-476, 1990), and the American with Disabilities Act (ADA) (PL 101-336, 1990), provide various mandates regarding assistance, services, and accommodations for individuals identified as having a functional impairment due to an emotional or behavioral difficulty. Consequently, there are a variety of educational and vocational supports available to students with EBD, including educational, vocational, and integrated supports. Programs and accommodations vary in intensity and levels of support, depending of the degree of functional impairment of the individual or population served. Although the literature is replete with research on interventions and support programs, the below discussion provides an overview of pertinent legislation and a representative of supports and services for young adults with EBD.

### *Relevant Legislation*

The American Disabilities Act (PL 101-336, 1990) and the Rehabilitation Act of 1973 (PL 93-112) are civil rights legislation designed to protect individuals with disabilities from discrimination and provide reasonable accommodations, when appropriate. Specifically, Section 504 of the Rehabilitation Act of 1973 prohibits discrimination based on disability in all institutions that receive federal funds, including



most colleges and universities (PL 93-112, 1973; PL 102-569, 1992). In addition to prohibiting discrimination towards individuals with disabilities, both Title II of the Americans Disabilities Act and Section 504 of the Rehabilitation Act require academic institutions to provide reasonable accommodations to students with disabilities, including EBD (Collins, Bybee, & Mowbray, 1998). Furthermore, Section 504 requires postsecondary institutions to inform applicants of the availability of academic accommodations, services, auxiliary aid, and the person or office responsible for coordinating these services. For rights afforded under both ADA and Section 504, individuals must have a verifiable disability to access their rights, register with the appropriate disability services program, and must provide documentation of their disability (Schuck & Kroeger, 1993; Werner, 2001).

In 1990, the IDEA (PL 101-476) mandated the formulation of transition plan for youth receiving special education services by the age of 16. The 1997 amendments added the requirement that the individualized education program (IEP) team develop a statement of a student's transition needs, including the courses necessary to achieve long term goals, by the time the student reaches the age of 14 (IDEA, PL 105-17). Transition services should address domains such as community experiences, employment and other post-school objectives, instruction, daily living skills, and functional vocational evaluations (Frank & Sitlington, 1997). Both the Rehabilitation Act of 1973 and the transition amendments to IDEA recognize the importance of Vocational Rehabilitation (VR), which involves programs run by state VR agencies that operate under federal law (Rehabilitation Act, 1973; 1992; 1998).

### *Educational Supports*

Postsecondary education is an important component of career development and enhancement. Indeed, according to Bellamy and Mowbray (1998) "education is a valued entity in this society, allowing many not only an opportunity to learn, but also to enjoy the benefits related to it, such as employment and status" (p. 401). Moreover, higher education is becoming increasingly integral to employability for all individuals (Mowbray, 1999). For individuals with psychiatric disabilities, there are additional benefits to attending a postsecondary institution, including increased structure to daily life, normalization, and hope (Weiner, 1999). Although enrollment of students with disabilities in postsecondary education has increased, these students are completing their programs of study at a lower rate than are their non-disabled peers (Stodden, Whelley, Chang, & Harding, 2001). Academic accommodations, as mandated by Section 504, meet the needs of most students with disabilities. However, some students, with more severe levels of functional impairment, may require more extensive services, such as supported education.

### *Accommodations*

The intent of academic accommodations and disability support services is to address the functional limitations a student is experiencing, thereby reducing the effects of an individual's disabling impairment (Rickerson, Souma, & Burgstahler, 2004; Shaw & Dukes, 2005). Functional limitations may include difficulty managing time and deadlines, difficulty concentrating on multiple tasks, extreme reactions to negative feedback, limited ability to tolerate interruptions, anxiety and confusion when given

instructions, fear in approaching figures of authority, difficulty with concentration, trouble initiating interpersonal contact, difficulty tolerating noise and crowds, difficulty in screening out environmental stimuli, and trouble maintaining stamina throughout the day (Frado, 1993). At most postsecondary institutions, accommodations are coordinated by disability support or disability services offices (Graham-Smith & Lafayette, 2004). Common accommodations include extended time or separate setting for examinations, extended time for assignments, note-taking, and permission to tape record class lectures (Rickerson et al., 2004, Shaw & Dukes, 2005).

Stodden et al. (2001), reporting the results of a NCPES (National Center for the Study of Postsecondary Education Supports) survey of services for students with disabilities attending postsecondary institutions, found the majority of the 3,000+ postsecondary universities and colleges surveyed provided services to students with disabilities. While these services varied in “quantity and quality,” the results indicated the most common support offered was testing accommodations, followed by note-taking, personal counseling, and advocacy assistance. Other frequently offered supports included organization skill assistance, career-related supports, and study skills (Stodden et al., 2001). Few institutions offered disability specific scholarships; and less than 50% of the responding institutions provided disability evaluations or assessments (Stodden et al., 2001). Graham-Smith and Lafayette (2004) also examined the accommodations for students with disabilities and found the following six distinct categories of services: resource referral, disability management, scheduling assistance, curriculum modifications, academic probation assistance, and graduation planning.

The literature examining these services represents a growing body of research focused on accommodations for students with emotional and behavioral difficulties (Eudaly, 2002; Rickerson et al., 2004). Because services are provided based on functional limitations, the accommodations for students with EBD are often similar or identical to supports for students with other disabilities. In addition to common accommodations such as extended time and separate rooms for testing, note-taking, tape recording of lectures, extended time for assignments, and flexibility regarding attendance, modifications for students with psychiatric disabilities may include reduced course loads, preferred seating, prearranged and regular breaks during class time and during the semester, and limited group work (Rickerson et al., 2004; Sharpe et al., 2004).

### *Supported Education*

Much of the literature examining services for students with EBD, particularly for those with significant functional impairments, has focused on supported education programs (SEPs). These programs were among the earliest endeavors to assist students with EBD attending postsecondary institutions, and they provide a variety of services across diverse settings in order to assist these students in achieving their postsecondary educational goals (Mowbray, Megivern, & Holter, 2003; Sharpe, Bruininks, Blacklock, Benson, & Johnson, 2004). In their survey of all supported education programs, Mowbray et al. (2003) identified more than 100 programs at various settings, including clubhouses, on-site (a postsecondary institution), and free-standing models. Of the 22 on-site programs, nine were located at four-year universities, whereas thirteen were at community colleges. Sharpe et al. (2004) offered an estimate of approximately 30 on-site

postsecondary supported education programs. Services provided by these programs include registration assistance, and academic support, as well as individualized counseling and direct services. Furthermore, the results of their survey suggest an increased demand for services for students with psychiatric disabilities, and these programs are expanding and succeeding (Sharpe et al., 2004).

Although the majority of SEP evaluations and studies have demonstrated positive outcomes for participants and communities (Bybee et al., 2000; Mowbray, Gutierrez, Bellamy, Szilvagy, & Strauss, 2003), there are still many barriers, both internal and external, that limit student participation and overall program success (Bellamy & Mowbray, 1998; Mowbray, Bybee, & Collins, 2001; Unger & Pardee, 2002). Students may not have access to a supported education program because the number of SEPs is still relatively small. In addition to challenges such as securing funding and hiring appropriately trained personnel, supported education programs also may face resistance from administrators, faculty, and students due to stigma and misconceptions regarding psychiatric disabilities (Collins et al., 1998; Mowbray et al., 2001). Despite these barriers, supported education programs have benefited students with EBD disabilities attending postsecondary institutions (Bybee et al., 2000; Mowbray et al., 2003; Unger, Pardee, & Shaffer, 2000). Unfortunately, the number of these programs is still relatively small and the majority of universities and community colleges do not appear to provide these services.

### *Vocational Supports*

Although the number of young adults with EBD attending postsecondary schools is increasing, the majority of this population enters the workforce, with varying degrees of success. Employment is a valued aspect of life, providing social status, opportunities for personal achievement, and financial independence (Mowbray et al., 1999). However, youth with disabilities often have trouble finding, securing and maintaining employment (Jolivette et al., 2000). Indeed, unemployment is a serious and persistent problem for individuals with EBD, particularly those with more severe difficulties. Training programs offered through vocational rehabilitation, particularly supported employment for individuals with significant functional impairments, may lead to more successful outcomes for youth transitioning into adults.

### *Vocational Rehabilitation*

Vocational Rehabilitation is important for many reasons; employment is a valuable and valued aspect of American culture, and individuals with EBD, particularly those with significant functional impairments, may require assistance in obtaining and maintaining employment. The purpose of vocational rehabilitation programs is to provide or arrange for training, medical, and other services to meet the needs of individuals with disabilities. Further, the aim of these services is to assist individuals acquire and maintain gainful employment (Rehabilitation Act, PL 105-220, 1998). State rehabilitation agencies are responsible for vocational programs, and provide services based on an Individualized Plan for Employment (IPE) (PL 105-220, 1998). Students who have received special education services often transition into vocational rehabilitation programs; these are

typically provided through agreements between state and local school systems and the vocational rehabilitation agency. In order to receive vocational rehabilitation services, an individual must have a mental or physical that results in a substantial impediment to employment; be able to benefit from receiving vocational rehabilitation services; and require vocational rehabilitation services to prepare for, secure, retain or regain employment. One of the most common tasks of vocational rehabilitation state agencies is to provide supported employment for individuals with significant disabilities (PL 105-220, 1998).

### *Supported Employment*

Supported employment is closely related to supported education (Drake et al., 2001, pg. 179), and is generally utilized by individuals with severe functional impairments (i.e. psychiatric disabilities, mental retardation, and traumatic brain injuries) (Corbett, Clark, & Blank, 2002). The federal definition characterizes supported employment as:

competitive work in integrated work settings...consistent with the strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the individuals, for individuals with the most significant disabilities for whom competitive employment has not traditionally occurred; or for whom competitive employment has been interrupted or intermittent as a result of a significant disability. (Bond, Drake, Mueser, & Becker, 1997, p.335)

These programs generally offer placements in competitive employment (i.e. jobs paying at least minimum wage). Supported employment offers specialized job training, job

coaches, transportation, individually tailored supervision, and assistive technology (Corbett et al., 2002; Drake et al., 2001). Studies (Cook, Lehman & Drake, 2005; Corbett et al., 2002; Drake et al., 2001) demonstrate the on-going support provided by supported employment increases rates for employment retention.

Cook et al. (2005) conducted a multi-site randomized, control of supported employment to examine the effect of integrated vocational rehabilitation and psychiatric services on successful work outcomes. Twelve thousand two hundred and seventy-three outpatients across seven nationwide sites with severe mental illness were randomly assigned to either an experimental supported employment program or to a “services as usual” condition (p. 1948). The participants were followed for two years, and data collected consisted of semi-annual in-person interviews, monthly services tracking, program ratings, and recording of paid employment. Further, they examined the frequency of competitive employment and of individuals working at least 40 hours per month (Cook et al., 2005). Results indicated that participants in the integrated psychiatric and vocational model were twice as likely to be employed competitively at least 40 hours per month (Cook et al., 2005). Further, they found that greater amounts of vocational services yield better employment outcomes than higher amounts of psychiatric services (Cook et al., 2005). However, models that utilized integrated vocational and psychiatric services were more effective than other types of models (Cook et al., 2005).

### *Integrated Supports*

Along with supports and services specifically provided for individuals pursuing their educational and employment goals, there are integrated programs that provide



assistance in multiple domains, including education, employment and community involvement. The Transition Independence Process (TIP) and the Youth Transition Program (YTP) exemplify programs that address the transition process across domains (Clark et al., 2000).

#### *Transition Independence Process (TIP)*

The purpose of the TIP system is to support and prepare young adults as they transition from adolescence to adulthood. This system provides services for individuals aged 14-22 and identified as SED. This individualized process:

- a) Teaches community relative skills; b) encourages completion of secondary education; c) provides exposure to community-life experiences; d) promotes movements into post-school employment, educational opportunities, living situation, and community life; e) transcends the age barriers typical of child versus adult services; and f) respects the self-determination of young persons (Clark et al., 2000, p. 30).

TIP system guidelines emphasize person-centered planning; that is, planning based on the young adult's strengths, interests, and values. Supports should also be individualized and coordinated across all transition domains. The TIP system serves as a "safety-net" of support, and focuses on increasing the young adult's competencies. Finally, the TIP system is outcome-driven, with the goal of successful transition from adolescence to adulthood (Clark et al., 2000).

Utilizing the TIP Case Study Protocol for Continuing System Improvement (Deschênes, Gomez, & Clark, 1999), based on Yin's (1994) case study method, the TIP system was examined in order to:

Identify and describe common features of practice as it relates to transition of students and young adults with SED, and to utilize the information in a system improvement framework, to identify system development successes to date as well as areas needing further planning and management attention. (Deschênes, 2002, p. 3)

Another purpose of the study was to establish baseline information for further tracking and monitoring of the program (p. 3). Ten youth, six males and four females, ages 17-18, participated in the study, and attended SED programs in a local school district near Tampa, Florida. Teachers, and formal and informal providers, as identified by the youth, were interviewed.

Findings indicated that the school system needs to incorporate more elements of the TIP system into their transition process. Strengths of the program included the valuing of diversity and match of interventions to cultural backgrounds, the knowledge of and commitment of staff, access to natural supports, knowledge of IEP meetings, and student access to community and school based services and supports that prepared youth for transition across all domains (Deschênes, 2002). Most program concerns centered on the IEP process. Specifically, students' strengths and interests were either not identified or were not consistent with students' priorities and goals. Further, goals were often general, rather than individualized to meet the students' needs, and few students and

family members attended or participated in IEP meetings (Deschênes, 2002). Other concerns included a lack of coordination among school personnel and other service providers, unequal access to resources and services, and a need for more vocational and on the job training (Deschênes, 2002).

### *Youth Transition Program (YTP)*

The Youth Transition Program (Benz, Lindstron, & Yovanoff, 2000) was developed to improve transition from adolescence to adulthood for young adults who experienced barriers to secondary completion and to improve post school outcomes, such as meaningful employment and career related postsecondary education or training (Benz et al, 2000; Massey, 2004). The YTP began as a collaborative effort by the Oregon Department of Education, the University of Oregon, the Oregon Vocational Rehabilitation Division, and local schools statewide (Benz et al., 2000). Began in 1990 in seven schools, the program is now operated in 80% of all statewide high schools. The YTP serves secondary youth with all disabilities, but students are typically referred due to additional barriers to successful transition. Services for individual students begin during their last two years of high school and continue through early transition years after high school, if needed (Benz et al., 2000). Students receive:

Transition planning focused on post-school goals and self-determination, and help to coordinate school plans with relevant adult agencies; b) instruction in academic, vocational, independent living, and personal-social content areas, and help to stay in school & obtain a completion document; c) paid job training while in the program, and help to secure employment or enter postsecondary training

upon leaving the program; and d) follow-up support services for up to two years after leaving the program, provided on as-needed basis (Benz et al., 2000, p. 511). Outside evaluations (Horne & Hubbard, 1995; Rogers, Hubbard, Charner, Fraser, & Horne, 1995) found that 90% of participants completed high school or a GED, 82% of young adults entered job training programs or had gainful employment after completing the YTP program, and 80% of YTP participants continued to seek education or employment 2 years after completing the program. Benz et al. (2000) conducted two studies of the program. The first study examined the relationships between education and transition outcomes for youth with disabilities. Data was collected during the 1997-8 school year and involved 709 participants, 74 of whom were identified with an EBD. Using logistical regression procedures, results indicated that students participating in the YTP for more than a year were more than twice as likely to graduate with a standard diploma (Benz et al., 2000).

The goal of the second study was to explore staff characteristics and program factors identified by YTP participants as the most meaningful and helpful in assisting them reach their transition goals (Benz et al., 2000). Participants were interviewed in 6 focus groups. A total of 45 students were selected by purposeful sampling in order to represent the diverse characteristics of the study population. Students reported they participated in the YTP because they were not progressing in their current high school programs and were looking for opportunities to obtain skills that would help them succeed (Benz et al., 2000). They also positively compared the YTP to the regular high school, finding that the YTP provided consistent support from staff, individualized

service to achieve transition goals, and reminders to complete requirements. The students also discussed the benefits of participating in the program, such as the attainment of specific skills and opportunities to explore postsecondary education and employment options (Benz et al., 2000).

#### *Summary of Current Supports and Services for Emerging Adults with EBD*

Although the supports and services for emerging adults with EBD varied in population and settings, they shared similar goals and objectives. The purpose of all educational, vocational and integrated supports was to improve transitional outcomes for young adults with disabilities, including EBD. They all also recognized the continued need for integrated services between secondary and postsecondary services and institutions.

#### Phenomenological Research Methods

“Phenomenology” refers to the philosophical and methodological perspectives that attempt to describe and interpret the essence of the phenomena that structure conscious experience. It is a philosophy of inquiry that seeks to describe, rather than explain, “what one perceives, senses, and knows in one’s immediate awareness and experience” (Moustakas, 1994, p. 26). Phenomenological inquiry is influenced by principles that have evolved since the discipline’s conception in the early 20<sup>th</sup> century, originating in the work of Edmund Husserl, Martin Heidegger, Jean-Paul Sartre, and Maurice Merleau-Ponty, among other foundational thinkers. Contemporary phenomenological research continues to reflect the traditions established by these

philosophers. Researchers such as Van Manen (1990) and Giorgi (1985) have applied these ideas to pedagogy and other areas of social sciences.

### *Principles of Phenomenology*

Different types of phenomenology, such as transcendental (Husserl, 1931; 1970), existential (Merleau-Ponty, 1962; Sartre, 1965), and hermeneutical (Gadamer, 1989), represent various ways in which philosophers approach and conceptualize and phenomenology.<sup>5</sup> However, phenomenologists, in their endeavor to describe the experience of a particular phenomenon, share similar concerns, such as nature of the conscious self, perception, and essences. The phenomenological process begins with a conscious self, who imagines, perceives, thinks, remembers, and judges (Ihde, 1979). Perception is an important aspect of phenomenology, as it is considered the primary source of knowledge (Husserl, 1970, pp. 608-609). Indeed, Merleau-Ponty (1962) identifies perception as the access to truth (p. xvi). Another important principle of phenomenology is the study of essences. Essence, as describe by Husserl (1931) is the universal quality or condition that makes the particular phenomenon or “thing” what it is (p. 43). In addition to these principles, transcendental phenomenological research methods also emphasize the principles of intentionality, noema, noesis and intuition.

### *Intentionality*

Intentionality is associated with the “internal experience of being conscious to something” (Moustakas, 1994, p. 28). In fact, intentionality is synonymous for consciousness itself, as human beings are always intentionally conscious of something (p.

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<sup>5</sup> This study will utilize transcendental phenomenology, as conceptualized by Husserl.

59). Intentionality guides the conscious self toward something, whether it is real or imaginary (Miller, 1984, p. 223). It is the act of becoming fully part of the world, and forming an inseparable connection (Van Manen, 1990). The intentionality of consciousness is comprised of the relationship between a noema and noesis (Husserl, 1971, p. 46).

### *Noema and Noesis*

The noema is what is presented, the appearance of the ‘thing’, whereas the noesis is subjective, the underlying meaning, the perception of what is experienced” (Moustakas, 1994, p. 71-72). In other words, noema refers to what appears; it is that which is experienced (Ihde, 1977). In contrast, the noesis is *the way* the “what is experienced” (p. 43). The noesis is constructed through perceptions, judgments, memories and feelings (Moustakas, 1994, p. 69). Simply put, the noema refers to the object, whereas the noesis is subjective (Sokolowski, 2001). The noema and noesis must be unified in order to understand the experience, and to reach the essences of a phenomenon. “Faithful description” is central to this procedure; indeed, the researcher must engage in “looking and reflecting, looking and reflecting again,” in order to acquire complete and accurate descriptions and discover hidden meanings in the described experiences (Moustakas, 1994, p. 70).<sup>6</sup>

### *Intuition*

Intuition is another central concept of transcendental phenomenology (Moran, 2000; Moustakas, 1994). Husserl considered intuition essential to describing phenomena

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<sup>6</sup> The process of unifying the noema and noesis will be explored later in the chapter.

because “it is the beginning place in deriving knowledge of human experience, free of everyday sense impressions” (Moustakas, 1994, p. 32). Intuition is directed toward both objects and intentionality, as one tries to understand the essence of a thing through memory, perceptions, and thoughts (Sokolowski, p. 405). Intuition exists at the highest stage of knowledge, and yields hard-won understandings and insights (Moran, 2000, p. 10).

### *Major Processes of Phenomenological Research*

Phenomenological inquiry is an exploration of an individual’s experience with a particular phenomenon. As a method of inquiry, phenomenology provides a researcher with the tools and structure needed to observe, examine, and interpret the complexity in the human experience by investigating the relationship between individuals and the world as they experience it (Pollio, Henley, & Thompson, 1997). Moustakas (1994) identified four major processes of phenomenological research, including the Epoche, Phenomenological Reduction, Imaginative Variation, and Synthesis of Composite Textural and Composite Structural Descriptions.

#### *The Epoche*

The Epoche, which is a component of the data collection process, requires the researcher to acknowledge his or her own presuppositions and prejudgments regarding the phenomenon being studied. The aim of the Epoche process is to allow the researcher to “learn to see what stands before our eyes,” rather than describe the topic of study as she perceives it (Moustakas, 1994, p. 33). The challenge of phenomenological research is that the researcher often knows too much about the phenomenon he or she wants to study



(Van Manen, 1990). Epoche, Greek for abstaining or staying away from, entails eliminating pre-suppositions, biases, and predispositions (Husserl, 1970). That is, the researcher must be “completely open, receptive and naïve in listening to and hearing research participants describe their experience of the phenomenon being investigated” (Moustakas, 1994, p. 22). Putting aside prejudgments and predilections allows the researcher to see things anew, from a fresh perspective. The researcher must bracket all preconceived notions, theoretical beliefs and conceptual biases regarding the phenomenon being studied (Creswell, 1998; Pollio et al., 1997). Bracketing requires the researcher to understand our assumptions, not to forget them, “to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow or concealing character” (Van Manen, 1990, p. 47).

According to Husserl (1970), it is essential for the researcher “to discover the nature and meaning of things as they appear and in their essence” (Moustakas, 1994, p. 26). However, it is a difficult, if not impossible, task to “allow a phenomenon or experience to be just what it is” (p. 86). Merleau-Ponty (1962) asserted it is impossible to achieve complete bracketing. The process of bracketing may fail for many reasons; for example, the researcher may judge a reflection as illogical, or may not recognize his or her own presuppositions (Pollio et al., 1997). Acknowledging that adopting a “suppositionless, pure ego state is in itself a supposition,” Moustakas (1994, p. 62) concedes that the Epoche is seldom achieved and requires patience and for the researcher to “stay with whatever it is that interferes until it is resolved and an inward cleaning is

achieved, an opening, an intention directed toward something with clarity and meaning” (p. 89).

Pollio et al. (1997) offer three methods to promote the success of the bracketing process. The first requires the researcher to explicitly acknowledge his or her reasons for investigating a certain phenomenon through either a personal statement or participating in a bracketing interview. Second, interpretations should be provided in the participants’ terms rather than the language used by a discipline, such as social sciences (p. 49). The third involves interpreting at least part of the interview text with a group that functions in a critical capacity (p. 49).

### *Phenomenological Reduction*

Phenomenological Reduction is one aspect of data analysis, and considers each experience singularly, developing a textural, or noematic, description “of the meanings and essences of the phenomenon” (Moustakas, 1994, p. 34). The noema refers to the “what;” therefore, a textural, or noematic, description recognizes and describes qualities of the phenomena, omitting nothing, and granting each perception equal value (p. 78). Specifically, Phenomenological Reduction involves the following steps: bracketing, horizontalizing, and finally, organizing the horizons and clustered themes into a logical textural description of the phenomenon (p. 97).

First, the process of reduction requires the researcher to bracket, or temporarily suspend assumptions and presuppositions about phenomena (Merleau-Ponty, 1962). The researcher must focus on the descriptions of the phenomena, the “what” that is being

studied. Bracketing entails the researcher focusing only on the question and the topic, setting aside everything else, including pre-suppositions and assumptions.

The next process, horizontalizing, requires reflection; the researcher views the phenomenon from different angles, letting it “be in its appearance.” Horizons refer to the textural meanings and non-repetitive elements of a phenomenon. The researcher remains with the phenomenon to the point of “exhausting what is offered during a particular time and place of perceiving and experiencing” (Moustakas, 1994, p. 92). However, it is important to note that it is impossible to exhaust the possibilities of experience. Another important aspect of horizontalizing is to check with others regarding what they think, perceive and feel. This step allows the researcher to revisit the phenomenon and perhaps find something new that changes her knowledge of the experience (p. 95). Although horizons are unlimited, the researcher must reach a stopping point. Then, overlapping, repetitive statements, as well as statements and observations irrelevant to the topic, are deleted, leaving only the horizons, or the invariant qualities, of the experience.

Finally, the horizons are then clustered into coherent themes; the elements of the experience are linked thematically until a full description is developed (Moustakas, 1994, p. 96). These horizontal themes are then organized into a textural, or noematic, description of the phenomenon. The goal of textural description is to recognize and describe the qualities of the experience. It is a “description of the meanings and essences of the phenomenon, the constituents that comprise the experience in consciousness, from the vantage point of an open self” (p. 34).

### *Imaginative Variation*

Another component of data analysis, Imaginative Variation seeks to derive structural, or noetic, descriptions of the essences of the experience described, that is, “the underlying and precipitating factors that account for what is being experienced” (Moustakas, 1994, p.98). As previously discussed, the noesis is constructed through memories, perceptions, thoughts and judgments. Whereas the textural descriptions derived from the Phenomenological Reduction process articulate the “what” of the experience, the structural descriptions yielded from Imaginative Variation address the “how” of the experience. The goal of Imaginative Variation is to uncover the underlying factors that may describe how the individual is experiencing the phenomenon (Moustakas, 1994, p. 98).

The steps of imaginative variation include:

1. Systematic varying of the possible structural meanings that underlie the textural meanings;
2. Recognizing the underlying themes or contexts that account for the emergence of the phenomenon;
3. Considering the universal structures that precipitate feelings and thoughts with reference to the phenomenon, such as the structure of time, space, bodily concerns, materiality, causality, relation to self, or relation to others;

4. Searching for exemplifications that vividly illustrate the invariant structural themes and facilitate the development of a structure description of the phenomenon. (p. 99)

Unlike textural description, structural description requires conscious acts of judging, thinking, recollecting and imagining. Imaginative Variation allows the researcher to obtain structural themes from the textural descriptions derived through the process of Phenomenological Reduction. However, it is important to note there are innumerable possibilities to describe the meanings and essences of an experience (p. 99).

#### *Synthesis of Composite Textural and Composite Structural Descriptions*

Finally, the Synthesis of Composite Textural and Composite Structural Descriptions involves unifying the elemental textural and structural descriptions into an integrated “statement of the essences of the experience of the phenomenon as whole” (Moustakas, 1994, p. 100). Textural and structural meanings are intimately and constantly connected. It is not possible to fully understand the “what” of the experience, without examining the “how” of the experience, and vice versa (Ihde, 1977, p. 50). As previously stated, the essences, or the conditions or qualities of an experience, are never completely exhausted. The textural-structural synthesis derived from the phenomenological research process embodies “the essences at a particular time and place from the vantage point of an individual research following an exhaustive imaginative and reflective study of the phenomenon” (Moustakas, 1994, p. 100)

## *Systematic Research Methods*

Moustakas (1994) organized phenomenological research method into four categories, Methods of Preparation, Methods of Collecting Data, Methods of Organizing and Analyzing Data, and Summarizing and Reflecting on Data.

### *Methods of Preparation*

The first category, Methods of Preparation, includes formulating and defining terms of the question, conducting a literature review, developing criteria for selecting and recruiting participants, and developing guiding topics or questions for the research interview. The research question is comprised of the following defining characteristics:

1. It seeks to reveal more fully the essences and meanings of human experience;
2. It seeks to uncover the qualitative rather than the quantitative factors in behavior and experience;
3. It engages the total self of the research participant, and sustains personal and passionate involvement;
4. It does not seek to predict or to determine causal relationships;
5. It is illuminated through careful, comprehensive descriptions, vivid and accurate renderings of the experience, rather than measurements, ratings or scores.

(Moustakas, 1994, p. 105)

Further, the research question should be derived from an intense interest, curiosity, or excitement, in a particular subject or problem. Unlike other modes of inquiry, the researcher's personal history focuses the core of the problem or topic (p. 104).

### *Methods of Collecting Data*

The Methods of Collecting Data stage involves the Epoche process, as discussed above, and conducting the phenomenological research interview. Data are collected through the long interview (Van Manen, 1990; Giorgi, 1985). Typically, the interview process begins with an informal, social conversation to create a relaxing, and to the extent possible, trusting atmosphere. The participant is then asked to focus on the experience in question and describe it as fully as possible. The interview process is informal and interactive, utilizing open-ended questions and comments. Although the researcher will utilize an interview protocol, it may be altered or varied depending on the responses of the participant, and the thoroughness of their description of the “full story” of phenomena (Moustakas, 1994, p. 114).

### *Methods of Organizing and Analyzing Data*

The processes involved in Methods of Organizing and Analyzing Data include developing descriptions and formulating themes based on the collected data (Moustakas, 1994, pp. 103-104). There are multiple methods of analyzing the data in phenomenological research. In his discussion of phenomenological data analysis, Moustakas (1994) suggests methods such as modified versions van Kaam (1959, 1966) and the Stevick (1971), Colaizzi (1973), and Keen (1975) methods of phenomenal data analysis. These methods utilize the processes of phenomenological reduction, imaginative variation and synthesis of meanings and essences as discussed above.

### *Summarizing and Reflecting on Data*

This final category provides the researcher an opportunity to summarize the study, and relate data to and distinguish from findings of the literature review. The researcher may also relate the study to future research, and to personal and professional outcomes. A discussion of the study's social meanings and relevance should also be discussed. Finally, the study is concluded with a consideration of the researcher's future goals (Moustakas, 1994, p. 182).

### Summary

The purpose of this literature review was to provide a theoretical context for the current study, and an overview of relevant research regarding the transition from adolescence to adulthood. Specifically, the chapter began with a discussion of the constructs of emerging adulthood and transition, followed by a consideration of the challenges of the transition process, for individuals with and without EBD. After this theoretical discussion, an overview of longitudinal studies examining the outcomes of emerging adults was provided. The chapter also reviewed research examining educational, vocational, and integrated supports and services, and pertinent legislation for these supports. An overview of phenomenology, the research methodology utilized for this study, was also included. This summary concludes with a review of the relevant gaps in the literature and the purpose of this study is revisited.

Emerging adulthood is a relatively new concept that considers the period between adolescence and adulthood (roughly ages 18 to 25) as a distinct life stage. The transition process is just one aspect of this period. Transition is an exciting and eventful process,



including developmental tasks such as entering adult roles, establishing satisfying relationships, attaining higher education or vocational training, and obtaining meaningful and gainful employment. Emerging adults, as they transition into adulthood, face many challenges, including a lack of a clear sequence of the major transitions into adulthood, economic fluctuations, and personal challenges such as developmental mismatches between desires and abilities. In addition to these challenges, young adults with EBD must also contend with possible cognitive and emotional delays and changes in institutional and familial supports. Further, the fragmented system of care for individuals with EBD complicates the transition process. There are also many factors, including theoretical and social constructs such as self-determination, resiliency and stigma that impact the transition process. Self determination, which emphasizes autonomy and self-direction, and resiliency, which provides an ability to succeed despite adversity, increase the likelihood of successful transition. However, stigma, which involves negative attitudes and prejudices towards difference, including emotional and behavioral difficulties, can often provide a barrier and negatively impact transition into adulthood.

Several longitudinal studies, including the NLTS and NLTS-2, NACTS, and YAICS examined the outcomes of individuals with EBD. The first three focused on students in special education or mental health systems, and the latter studied young adults in the community. All four studies indicated poor outcomes across transition domains, including education, employment, community involvement, and social relationships.

Due to poor outcomes for young adults with EBD, legislation has been created to mandate services for this population. The 1990 and 1997 amendments to IDEA required

transition services for students receiving special education services, and civil rights laws such as ADA and the Rehabilitation Act, prohibit discrimination based on disability and mandated accommodations and vocational rehabilitation, for qualifying individuals.

Supports and services have been developed in compliance to this legislation.

Educational supports include accommodations at the postsecondary level and supported education programs for individuals with severe functional impairments. These services, when and where implemented, have resulted in improved outcomes for young adults with EBD. Vocational supports, under the auspices of vocational rehabilitation, have improved employment outcomes for individuals with EBD. Supported employment programs are the most frequently implemented and are more successful when they utilize integrated vocational training and psychiatric treatment. Integrated supports, such as the TIP system and the YTP have met with varying degrees of success, but also emphasize the need for coordinated services between secondary and postsecondary institutions, across all transition domains.

However, few studies consider the qualitative experiences of emerging adults with EBD who are transitioning from adolescence to adulthood. Some research studies, particularly those examining supported education programs and integrated programs, do utilize qualitative methods such as individual and focus group interviews. However, these studies do not consider the personal experiences of young adults with EBD, or how they understand and live with their disabilities. Even fewer studies consider the experiences of emerging adults with EBD who are pursuing their vocational and/or educational goals.

The purpose of this study is to acquire a better understanding of the experiences of young

adults diagnosed with an emotional or behavioral difficulty and who are working towards their desired vocational and/or educational goals.

## CHAPTER THREE

### METHOD

#### Purpose

The purpose of the study was to acquire a better understanding of the experiences of young adults diagnosed with an emotional or behavioral difficulty (EBD) and who are working towards their desired vocational and/or educational goals. In addition to focusing on the experiences of young adults with EBD, this study identified individual perceptions of supports and services that are integral to a successful transition from high school to vocational or educational settings.

#### Central Questions

The following questions were addressed in this study:

1. How do selected emerging adults perceive and describe the experience of being diagnosed and living with an emotional or behavioral difficulty?
2. How do selected emerging adults with emotional or behavioral difficulties perceive and describe the impact of their disability on their transition experience and ability to reach their future goals?
3. How do selected emerging adults with emotional or behavioral difficulties perceive and describe the role of supports that contribute, and those that could contribute, to achieving their desired vocational and educational goals?

## Epistemological Framework: Phenomenology

Phenomenology is a philosophy of inquiry that seeks to describe “what one perceives, senses, and knows in one’s immediate awareness and experience” (Moustakas, 1994, p. 26). It is the “study of essences” (Merleau-Ponty, 1962, p. vii), a description of a phenomenon, that is, a thing that appears to or is constructed by the mind, such as physical objects, thoughts or emotions (Ehrich, 2003). Phenomenological research attempts to describe things as they are experienced, to return to the “things themselves” (Husserl, 1970, p. 252). The purpose of phenomenology is to describe, rather than explain phenomena (Ehrich, 2003). Indeed, the phenomena must be understood before explanations are offered or imposed (Moran, 2000).

The researcher chose to conduct a phenomenological study because she is interested in the experiences of young adults with emotional or behavioral difficulties and how they make meaning of their lives (i.e., how they interpret constructs such as stigma and recovery). The principal aim of this study is to capture the lived experiences of young adults with emotional or behavioral difficulties. More specifically, this study examines how students’ beliefs interact with their transition experiences in the process of creating meaning. According to Van Manen (1990), “lived experience is the starting point and end point of phenomenological research. The aim of phenomenology is to transform lived experience into a textual expression of its essence” (p. 42). The purpose of this study was to transform the lived experiences of emerging adults with EBD, into a textual expression of their essences, and to provide a description of the specified phenomena.

Creswell (1998) suggests that phenomenologists make *a priori* decisions to examine the “meaning of experiences” for individuals (p. 86). The phenomenological process begins with a conscious self, who imagines, perceives, thinks, remembers, and judges (Ihde, 1979). Further, subjective experience mediates objective understanding (Creswell, 1998). That is, the “perception of the reality of an object is dependent on a subject” (Moustakas, 1994, p. 27). The researcher is, therefore, challenged to unify the “real and the ideal” by merging what is “really present with what is imagined as present” (p. 27).

The concepts of intentionality, noema and noesis, are integral to this process. Intentionality is associated with the “internal experience of being conscious to something” (Moustakas, 1994, p. 28) Intentionality is the act of becoming fully part of the world, forming an inseparable connection (Van Manen, 1990). Intentionality consists of a noema and a noesis. The noema is what is presented, the appearance of the ‘thing’, whereas the noesis is subjective, the underlying meaning, the perception of what is experienced (p. 71-72). The noema and noesis must be unified in order to understand the experience. “Faithful description” is central to this procedure; indeed, the researcher must engage in “looking and reflecting, looking and reflecting again,” in order to acquire complete and accurate descriptions and discover hidden meanings in the described experiences (p. 70).

### Methodological Overview

Moustakas (1994) describes several categories of systematic phenomenological research, including Methods of Preparation, Methods of Collecting Data, and Methods of

Organizing and Analyzing Data (p. 104). The first category, Methods of Preparation, includes formulating and defining terms of the question, conducting a literature review, developing criteria for selecting and recruiting participants, and developing guiding topics or questions for the research interview. Second, the Methods of Collecting Data stage involves conducting the phenomenological research interview. The processes involved in Methods of Organizing and Analyzing Data, the third category of systematic phenomenological research, include developing descriptions and formulating themes based on the collected data (pp. 103-104). A fourth category, provides the researcher an opportunity to summarize the study, relate data to and delineate from findings of the literature review, relate study to future research, and relate the study to personal and professional goals, as well as relevance and social meanings (p. 182).

The major processes of phenomenological research include the Epoche, Phenomenological Reduction, Imaginative Variation, and Synthesis of Composite Textural and Composite Structural Descriptions.<sup>7</sup> Briefly, the Epoche, which is a component of the data collection process, requires the researcher to acknowledge their own presuppositions and prejudgments regarding the phenomenon being studied. The aim of the Epoche process is to allow the researcher to “learn to see what stands before our eyes,” rather than describe the topic of study as she perceives it (Moustakas, 1994, p. 33). The methods of analysis are Phenomenological Reduction and Imaginative Variation. Phenomenological Reduction considers each experience singularly, developing

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<sup>7</sup> These terms are discussed in greater detail in the literature review, and will be addressed as appropriate in this chapter.

a textural description “of the meanings and essences of the phenomenon” (p. 34). A textural description explicates the phenomenon by recognizing and describing qualities, granting each perception equal value, and elements of the experience are linked thematically until a full description is developed (p. 96). The goal of Imaginative Variation is to derive structural descriptions of the essences of the experience described, that is, “the underlying and precipitating factors that account for what is being experienced” (p.98). Whereas the textural descriptions derived from the Phenomenological Reduction process articulate the “what” of the experience, the structural descriptions yielded from Imaginative Variation address the “how” of the experience. Finally, the Synthesis of Composite Textural and Composite Structural Descriptions involves unifying the elemental textural and structural descriptions into an integrated “statement of the essences of the experience of the phenomenon as whole (p. 100).

#### Methods of Preparation

#### *Population and Sampling*

Prevalence rates of individuals with EBD vary in the literature, due to inconsistency in how disabilities are defined and measured. However, most estimates of young adults (ages 16-25) with a mental or psychiatric disorder range from 18% to 23% (Aalto-Setala et al., 2001; Cohen et al., 1996; Friedman, 1996). This number is consistent with the estimates of adults (ages 18-64) diagnosed with a psychiatric or mental disorder (Stoddard & Kraus, 2004; U.S. Department of Health and Human Services, 2000). The types of EBD vary depending on the ages sampled, and whether or



not individuals were receiving services. In a study (Vander Stoep et al., 2000) of 16 to 17 year-olds, the most prevalent diagnoses were disruptive behavior disorders, substance-related disorders, anxiety disorders, and depressive disorders, respectively (Clark & Foster-Johnson, 1996). Studies examining older populations (17-25) found that disruptive behavior disorders were less common than other disorders, such as depressive disorders, anxiety, substance abuse, and personality disorders (Aalto-Setala et al., 2001; Davis & Vander Stoep, 1997).

Purposeful sampling procedures were used for this study; Sandelowski (1995) differentiates between “convenience” and “purposeful” sampling. That is, individuals were selected to participate purposefully, based on certain criteria, rather than willingness, convenience, or availability to participate. Specifically, individuals selected for the study were between the ages 18 to 25, consistent with Arnett’s (2006) definition of emerging adulthood. Participants were also identified as having one of the following Axis I psychiatric disorders, as classified in the DSM-IV-TR: schizophrenia, mood disorders, including major depressive disorder and bipolar disorders, and anxiety disorders (American Psychiatric Association, 2000). Childhood disorders such as conduct disorders, Autism Spectrum disorders were excluded because this study is exploring the experiences of emerging adults (Clark & Davis, 2000). Finally, participants were enrolled in a postsecondary educational institution (e.g., community college, university).

#### *Participant Recruitment and Sample*

Flyers (Appendix A) were posted in the Counseling and Wellness Center at New College (which serves students attending New College and the USF Sarasota-Manatee

campus), the University of South Florida's Office of Student Disability Services (Sarasota-Manatee campus), and on the University of South Florida's Honor College electronic blackboard. In addition, the researcher described her study to students enrolled in the USF special education program.

Once interested young adults voluntarily contacted the researcher, she explained the study's purpose, confidentiality, consent, financial incentives, and data collection procedures in greater detail to potential participants. This contact also provided the researcher with an opportunity to verify that the individual meets the criteria for participating in the study, as previously described. Potential participants were asked to provide a verbal commitment to participate in a minimum of two interviews, to take place at a time and location convenient to the participant. Participants were given \$50 as a token of appreciation for their participation in the study.

Sixteen college students volunteered for the study, twelve females and four males; nine of the volunteers read the research announcement on Honors College electronic blackboard, five saw the flyer at the Counseling and Wellness Center, one student was referred from the Office of Student Disability Services, and one student heard about the study during a special education class. The first five volunteers meeting the criteria were selected for the study.

## Data Collection

### *Epoche and the Role of the Researcher*

The challenge of phenomenological research is that the researcher often knows too much about the phenomenon she wants to study (Van Manen, 1990). Epoche, Greek

for abstaining or staying away from, entails eliminating pre-suppositions, biases, and predispositions (Husserl, 1970). That is, the researcher must be “completely open, receptive and naïve in listening to and hearing research participants describe their experience of the phenomenon being investigated” (Moustakas, 1994, p. 22). Putting aside prejudgments and predilections allows the researcher to see things anew, in a fresh manner (Moustakas, 1994). The researcher must bracket all preconceived notions, theoretical beliefs and conceptual biases regarding the phenomenon being studied (Creswell, 1998; Pollio et al., 1997). Bracketing requires the researcher to understand our assumptions, not to forget them, “to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow or concealing character” (Van Manen, 1990, p. 47).

According to Husserl (1970), it is essential for the researcher “to discover the nature and meaning of things as they appear and in their essence” (Moustakas, 1994, p. 26). However, it is a difficult, if not impossible, task to “allow a phenomenon or experience to be just what it is” (p. 86). Merleau-Ponty (1962) asserted it is impossible to achieve complete bracketing. The process of bracketing may fail for many reasons; for example, the researcher may judge a reflection as illogical, or may not recognize his or her own presuppositions (Pollio et al., 1997). Acknowledging that adopting a “suppositionless, pure ego state is in itself a supposition,” Moustakas (1994, p. 62) concedes that the Epoche is seldom achieved and requires patience and “stay with whatever it is that interferes until it is resolved and an inward cleaning is achieved, an opening, an intention directed toward something with clarity and meaning” (p. 89).

Pollio et al. (1997) offer three methods to promote the success of the bracketing process. The first requires the researcher explicitly acknowledge his or her reasons for investigating a certain phenomenon through either a personal statement or participating in a bracketing interview. Second, interpretations should be provided in the participants' terms rather than the language used by a discipline, such as social sciences (p. 49). The third involves interpreting at least part of the interview text with a group that functions in a critical capacity (p. 49).

For the purposes of this study, the researcher wrote a personal statement (Appendix B) detailing her history and interests regarding the phenomenon (Pollio et al., 1997). This Epoche process allowed the researcher to consider her reasons for examining this topic, to become more aware of her assumptions about the meaning of the phenomenon being explored, and provide a description of her current understandings of the topic (p.48). The researcher engaged in the Epoche process just prior to, and after, conducting interviews. Furthermore, the researcher maintained a reflexive journal throughout the data collection and analysis processes. The researcher used this journal to reflect on a variety of issues, including her personal values and biases that may have influenced data collection or analysis.

#### *In-depth Interviews*

The researcher conducted one in-depth interview with each participant, utilizing a long interview protocol (Appendix C), as recommended by Creswell (1998), Giorgi (1985), and Van Manen (1990) for phenomenological studies. Because participants were asked to describe an experience of particular phenomena, they were given an opportunity

to share their story of the experience (Moustakas, 1994; Van Manen, 1990). Also, the researcher asked questions designed to evoke detailed descriptions of specific experiences (Pollio et al., 1997, p. 30). The research altered or varied the interview protocol when necessary, adding questions to probe further and deleting questions that were answered in the participants' initial description of their experience. Flexibility was important to allow for answers to be fully explored, responsiveness to relevant issues offered by the interview, and to address topics in an order that is comfortable to the participant (Legard, Keegan & Ward, 2003, p. 141).

The interviews were informal and conducted at a time and venue agreed upon by the participant and the researcher. Interviews took place at various locations, including a library, local coffee shops, and outdoor settings on college campuses. Before each interview, the researcher engaged the participant in casual conversation for about ten to twenty minutes, depending on the participant. The researcher then read the informed consent form and allowed for questions and responses. After the participant signed the consent form, the researcher began recording. The duration of the in-depth interviews ranged from 40 minutes to 1 hour and 47 minutes. At the conclusion of each interview, the researcher stopped the recording and scheduled a follow-up meeting that was utilized for member-checking, in order to clarify responses and check for accuracy and representativeness (Creswell, 1998). These follow-up interviews ranged from ten minutes to 35 minutes, and took place no later than two weeks after the initial interview. No participant changed or deleted information from the selections, and all felt their thoughts were accurately represented. When necessary, participants answered additional

questions in order to clarify or elaborate previous statements. Interviews were recorded using an Olympus digital voice recorder WS-310M and transcribed by the researcher.

### *Pilot Study*

Before interviewing selected participants, the researcher interviewed an adult volunteer utilizing the attached protocol and the previously described procedures. The purpose of this pilot study was two-fold: to identify and remove irrelevant or unnecessarily upsetting questions; and, to check the credibility of the selected questions and ensure the interview protocol and procedures promote the purpose of the study. Because the researcher and participant already knew each other, they spent time “catching up” and engaging in casual conversation. After explaining the process and obtaining informed consent, the researcher started the recorder and began the interview, which lasted 70 minutes. After the interview, the researcher scheduled a follow up meeting. At that time, the participant was given the opportunity to verify her responses and comment on the interview protocol. The participant did not suggest that any questions should be removed, but did suggest that the researcher add questions about how the participants’ EBD affected intimate relationships and drug or alcohol abuse. After transcribing the interview, the researcher met with two committee members to discuss the transcripts, the participant’s suggestions, and the interview protocol. They reached consensus that the interview protocol adequately elicited the participant’s experience transitioning from adolescence to adulthood. They also agreed that the protocol should be modified, as appropriate, during individual interviews.

## Data Organization, Analysis, and Synthesis

The researcher was guided by Moustakas' (1994) modified version of van Kaam's (1959; 1966) method for analyzing data for a phenomenological study. Data were analyzed using the following seven steps: listing and preliminary grouping, reduction and elimination of horizons to determine invariant constituents, clustering and thematizing the invariant constituents, final identification and validation of the invariant constituents and themes by application, construction of individual textural descriptions, or analysis, for each participant, development of impressions of each participant, and construction of a composite description of the meanings and essences of the experience, representing the group as a whole.

First, for each transcript, the researcher listed every expression relevant to the experience. Next, these statements were reduced to non-repetitive and relevant statements. Each expression was tested for two requirements: 1) Does it contain a moment of the experience that is a necessary and sufficient constituent for understanding it? and, 2) Is it possible to abstract and label it? (Moustakas, 1994). If the expression met these requirements, it was identified as a horizon of the experience. The horizons that remained from this process of reduction and elimination comprised the invariant constituents of the experience. The third step involved clustering the invariant constituents and giving these clusters thematic labels. Fourth, the research validated the invariant constituents and thematic clusters by checking for textual evident from the complete transcript for each participant. Fifth, the researcher then constructed an analysis, comprised of an individual textural description of their experience, including word for

word examples from the interview (Moustakas, 1994). This is the noemic account of the experience, that is, the “what” of the experience. The sixth step involved the researcher constructing impressions of the meanings and essences of the participant’s experience, or the noetic account, incorporating the invariant constituents and themes developed earlier. That is, the researcher attempted to understand how the participants made sense of their transition experience. Finally, the researcher constructed a Composite Description of the recurring themes of the meanings and essences of the experience that represented the group as a whole (Moustakas, 1994).

### Ethics

The researcher obtained IRB approval for this study to ensure that the rights and welfare of participants are protected from undue emotional, physical and emotional harm. Participants were required to sign a University of South Florida Institutional Review Board informed consent form (Appendix D) prior to participating in the study that makes certain potential participants understand the nature of the research and the interviewee’s participation. Furthermore, the researcher established clear agreements with the research participants, and provided full disclosure of the nature, purpose and requirements of the research study, including the analysis of data. These details include the number and length of interviews, the venue at which the interviews will take place, the topic of study, an understanding that the interviews will be audio-recorded, and provisions for privacy (Legard et al., 2003, p. 196). The participants were also provided with phone numbers to the university counseling center and county crisis center, if needed. In addition, they were informed they may terminate the interview at any time.



In order to ensure the privacy of participants, the researcher did not utilize participants' names or other identifying information in notes, transcripts, or in the findings of the document. All written information and interview transcripts were stored in a locked cabinet to provide an additional measure to maintain confidentiality. Participants were also given an opportunity to review the transcripts of their interview, and confirm or alter research data in order to be consistent with his or her understandings of the experience.

One participant became visibly upset during her interview. The researcher stopped recording and asked her if she wanted to stop the interview; however, the participant said she was fine and wanted to continue the interview. The researcher debriefed all participants after being interviewed to reach closure (to the extent it is possible) on their experience in this study. When asked to reflect upon the interview process, all the participants stated they found it to be a positive experience. Finally, the researcher provided her phone number and invited participants to contact her if they have questions or concerns regarding the interview(s). One participant emailed the researcher to inform her that she received a job offer she discussed during the interview, but no participants called the researcher.

### Credibility

According to Miles and Huberman (1994), credibility refers to the "truth value" of a study (p. 278). Creswell (1998) suggests several approaches to enhance credibility in a qualitative study, including triangulation, audit trails, member checks, the use of thick, rich description, and clarifying research bias. Further, he recommends the use of at least

two techniques to ensure credibility. For this study, the researcher used the following techniques: clarifying research bias, member checking, and the use of thick, rich description. Clarifying research bias involves the researcher to comment on biases, prejudices, and experiences that may influence or shape interpretations (Creswell, 1998, p. 202). The researcher engaged in the bracketing process discussed above and wrote a personal statement that included possible preconceptions and biases. Further, the researcher maintained a reflexivity journal (Carney, 1990), in which she documented changes in design, interview approaches and associated thoughts. Lincoln and Guba (1985) assert that member checking is the “most critical technique for establishing credibility” (p. 314). Therefore, participants were given the opportunity to read transcripts of their interviews, provide alternate language, and verify themes or observations (Stake, 1995, p. 115). Finally, writing in thick, detailed description enables the reader to consider if the account makes sense or seems convincing or plausible (Miles & Huberman, 1994, p. 279).

## CHAPTER FOUR

### RESULTS

The results of this study are presented in terms of the participants' stories, as it relates to their diagnosis and transition, salient themes of their experiences, underlying structures that permeate their experiences, and a composite description of the participants' transition experiences. The research questions are addressed throughout each of these components. Although the participants and the researcher sometimes refer to the transition experience from high school to college, it is important to note that the participants are still in a transition from adolescence to adulthood, albeit at different stages, relevant to their ages and recency of diagnoses.

For each individual, an overview of the participant's story as it relates to their EBD and their current goals and pursuits, is provided. Following this overview is an analysis that identifies relevant themes, using excerpts from the participant's interview to illustrate those themes. Next, the researcher provides her "impressions" of the participant's experience, discussing apparent structures that permeate the individual's description. Finally, a composite of the participants' experiences is provided, in which the researcher identifies and discusses recurring themes. The following research questions are addressed throughout the individual stories, analyses, impressions, and composite of the participants' experiences:

1. How do selected emerging adults perceive and describe the experience of being diagnosed and living with an emotional or behavioral difficulty?
2. How do selected emerging adults with emotional or behavioral difficulties perceive and describe the impact of their emotional or behavioral difficulties on their transition experience and ability to reach their future goals?
3. How do selected emerging adults with emotional or behavioral difficulties perceive and describe the role of supports that contribute, and those that could contribute, to achieving their desired vocational and educational goals?

#### Participant Demographic Information

The participants included one African-American and four Caucasian females, ranging in ages from 18 to 24. One participant was diagnosed with bipolar disorder, one with generalized anxiety disorder (GAD) and two were dually diagnosed as having depression and GAD. Dani<sup>8</sup> and Lisa students attend a small independent honors college in southwest Florida that serves highly motivated and self-directed students. Rather than using a traditional grading system, students complete contracts that allow them to develop an individual academic program. Kristi and Tara attend a large urban university, and Beth is enrolled at branch campus of this university, in a metropolitan fringe area, which serves commuter students. Dani and Lisa receive services from a campus Counseling and Wellness Center. Beth utilizes services from the Office of Student

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<sup>8</sup> All names are pseudonyms

Services. Tara receives treatment from a private medical doctor, and Kristi does not receive any treatment for her EBD.

### Participants Overview, Analyses, and Researcher's Impressions

#### *Dani*

Dani, an engaging, Caucasian, 20 year old female with short, wavy brown hair and a bright smile, is attending a small independent honors college. She is an intelligent and ambitious student, and will be able to complete her degree in Religious Studies in three years. However, she is unsure if she is ready to graduate next year and leave the “cocoon” of her current setting. Throughout the interview, she was energetic and expressive, both verbally and non-verbally. Her responses were articulate and punctuated with laughter, at times ironic and/or self-deprecating.

She was originally diagnosed with depression when she was 13 years old, after her parents discovered a letter she wrote to a friend, which she now describes as “terribly angsty and terribly dramatic (with a smile).” Her mother read the letter because she noticed a change in Dani’s behavior and moods. In the letter, she wrote “I don’t know if I want to go on” and other expressions of depression and potential suicidal behavior. Her parents immediately took her to a psychologist, who recommended she see a psychiatrist. Once diagnosed, Dani went to a series of different psychiatrists and was prescribed various medications, including Paxil,<sup>9</sup> an SSRI<sup>10</sup> and Wellbutrin<sup>11</sup>, to treat her depression.

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<sup>9</sup> Paxil is a SSRI used to treat depression. Its generic equivalent is paroxetine.

<sup>10</sup> SSRI is an abbreviation for selective serotonin reuptake inhibitors, commonly prescribed drugs for treating depression. SSRIs work by inhibiting the reuptake of serotonin, an action which allows more serotonin to be available to be taken up by other nerves.

<sup>11</sup> Wellbutrin is a psychotropic medication used to treat depression. Its generic equivalent is bupropion.

Unfortunately, these did not “help (me).” Although she was not diagnosed with bipolar disorder until she started attending college, a psychiatrist put her on a combination of Zoloft<sup>12</sup> and Depakote,<sup>13</sup> “apparently somebody thought I had bipolar disorder but didn’t tell me...somebody had an idea, and decided to leave me and my family out of the loop.”

She also went to several therapists during her teenage years, but did not find it helpful. “One therapist told me she was going to Baker Act me if I did not talk about my grandfather’s death...and I was 14 and like, no way, and absolutely refused...I told my parents I would not see her any more.” Prior to attending college, she was diagnosed with severe clinical depression, “whatever that means” and once again went to therapy. “I was 17 at the time, and she wanted me to draw and paint pictures and stuff...I was like, I drove myself here, I don’t need finger paints.” Although she did receive treatment as an adolescent and teenager, it was not consistent or particularly helpful. She also was admittedly resistant to supports, “I just went through most of middle and high school refusing help from my family, friends, and completely cutting anybody out.”

When Dani first started attending college, she felt it was “a really nice transition...I was able to be on my own.” She was not taking medication or in counseling during the first semester and:

Started getting really, really low, and doing badly in my classes... I think I just accidentally wandered in the counseling center one day; I was on the verge of tears or something. I was like, “Hi, is there a counselor that can talk to me?” I

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<sup>12</sup> Zoloft is a SSRI that is used to treat depression and panic disorders. Its generic equivalent is sertraline.

<sup>13</sup> Depakote is a mood stabilizer used to treat bipolar disorders. Its generic equivalent is valproic acid.

didn't even know what was going on with me. It was one of those horribly low streaks when it was like...I think it was hot outside and I was wrapped in a big sweatshirt and just like "someone help me" and they got me an appointment 20 minutes later.

The psychiatrist diagnosed Dani as "really completely bipolar," and started her on medication and talk therapy.

Her first year of college was difficult because "we had a really hard time getting my medication regulated and getting me to take it." During the periods when Dani did not take her medication, she experienced mood swings and would often isolate herself. "I'd just sit inside with the windows shut, listen to music, sometimes to talk to my boyfriend online, he lives up in Arkansas for school. And just like not leave unless I have to go to class." She also considered leaving school because of her feelings of depression and stress, "There were definitely a couple of times when I would call my parents crying and want to go home and it was a pretty rough first year... when my meds were messed up or I wasn't taking them." Dani is currently taking Lamictal<sup>14</sup> and participating in therapy. She remains ambivalent regarding her medication, but recognizes that it is helping her, both socially and academically:

It (going off medication) made me realize it is a lot easier to go through this crap if you realize you have someone who has your back and it is nice to have people say you are not crazy, (and) it is a chemical thing.

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<sup>14</sup> Lamictal is a mood stabilizer used to treat bipolar disorders. Its generic equivalent is lamotrigine.

She also has developed numerous coping strategies, such as a support system of friends, walking, and cooking. She describes herself as “very stubborn and strong,” and is determined “to be a happy person.” She also stated that attending college has been “a positive experience overall.”

After graduating, Dani plans to work in the Teach America program for two years. Her ultimate goal is to move to Chicago with her boyfriend and become an elementary or middle school teacher. She is currently the co-director of a summer theatre program for kids in Gainesville and mentors 8<sup>th</sup> and 9<sup>th</sup> grade girls who are considered “at risk” because they “get low grades or have a bad family situation.” Several times during the interview, Dani expressed a desire to help others and be a source of strength for others.

She believes that having an EBD has influenced her goals, stating:

I guess having bipolar has made me more sympathetic to others...I can't avoid my bipolar, some people can't avoid that their parents work two jobs and are never home to help them. Everybody have some issues, and there has got to be someone who can be there regardless of what they have going on.

She also believes that having an EBD has made her more empathetic to young people, particularly girls, who are struggling, “I had a rockier time with it (middle and high school) than others so I feel like I have a lot to offer girls that age.”

#### *Analysis of Dani's Experience*

Dani's experience transitioning from adolescence to adulthood has been complicated by having an emotional difficulty:



In a way, it has kind of made me grow up more quickly than everyone else. They (other students) are still in this rebellious, partying mode...I have this constant little voice that's like, "This is not good for you." And I do think I have less fun than them and they do have an easier stress relief, like drugs, alcohol, partying, but I can't deal with that stuff...I feel they have it a little easier.

Her description of her experience reveals four core themes that impact her ability to achieve her goals: 1) Coming to terms with diagnosis and medication; 2) Finding social acceptance and understanding; 3) Establishing and maintaining formal and informal support systems; and, 4) Developing coping strategies.

*Theme One: Coming to Terms with Diagnosis and Medication.* Because Dani was originally on medication for depression and later diagnosed with bipolar, she has been prescribed many different types of medication and has "had a lot of unsuccessful trials." She would stop taking medication because she felt it wasn't working:

The problem is when you are on medication for depression when you have something else, it treats it some of the time but not always because it is not the same thing. So for me, I was like, "Whatever, my medication doesn't work anyway," so I would go off it and be happy for a while, and then not, and of course (I was experiencing) symptoms of bipolar and not depression.

She finds that "Lamictal generally works" and currently "everything seems to be good."

However, Dani expresses ambivalence regarding her diagnosis;

Bipolar (pause) it kind of fits. I don't know, I still am not sure if I am 100% sure if I agree with their diagnosis...I mean the medication seems to be working, so I

guess that is something would point to be their being correct, but I don't know, I feel like there are a lot of symptoms that I don't show.

She states that she does not have a "normal" case of bipolar because she does not fit the typical image of a person with bipolar disorder. She does not see herself as "that extreme" or exhibiting symptoms of someone with a bipolar disorder:

I don't think I spend any more than my other friends, or spend money I don't have, and I know that is one of the symptoms. And I've been told that the mood changes are like every week to three weeks, but mine are like ten times a day. So apparently I am between bipolar I and II, so it is complicated.

Although she is unsure if she agrees with her diagnosis of bipolar, being diagnosed has:

Actually been kind of a relief...for me my depression has always been I've felt like I've been incredibly sad (pause) there is no cause and effect, nothing you can do to fix it...So it was kind of relieving actually, to be like, "Okay, I am not crazy for always being sad. There is actually a chemical thing going on, and there is a way to treat it."

Dani's attitude towards taking medication fluctuates because of its impact on her life; she feels that she has to choose between being "healthy" and being "like other college students." Dani feels taking medication limits her both socially and academically. Socially, it is:

Hard because (long pause) as a college student, I have a lot of friends who party a lot and everything and on these medications...if I was to go out and do keg stands like my friends are doing, it would kill me, so like I have to be constantly be

aware and have to worry about things like my safety, things that my friends don't have to, so sometimes I feel left out or I just stay in my dorm.

She sees it as a choice that has to be made, "it's hard to decide if I value my physical and mental health more than being a typical student." In terms of academics, she feels she accomplishes less when she is on medication:

When I am off my medication...if I'm in a high, I'll get a months worth of work done in a night, no joke, I'll read a 1000 pages in a night. When I am on them (the medication), I'll just do what I need to do and won't do anything extra. I don't work ahead or anything.

Again, Dani feels like she is forced to make a choice, and that there is a cost to taking medication:

Sometimes I just wish I could go off of them for a couple of months and take advantage of the manic stage and get my work done for the semester (pause) it is frustrating, because it is like a choice, between my grades and my health. What do you put first, yourself or your grades?

Although she feels that taking medication can have a negative impact on her life, she recognizes that not taking medication is "much worse...I become really, really socially anxious, almost to the point of panic attacks." She then isolates herself, not leaving her room and "crying a lot." Dani is also affected academically when she is not on her medication:

When I am off of them and I'm in a low, I won't do anything and get a month behind and won't get anything done...one semester, because of medications being

unregulated, and I couldn't concentrate, I was almost at risk of not passing that contract that semester.

Because she "acts like a completely different person" when she does not take medication, Dani is also concerned about how it affects her identity, or if it changes who she is:

I don't know, it's kind of hard because when you medicate yourself, there is always this confusion, like, am I who I am when I am on medication? Is the real me this crazy person when I am not on medication? So that is really confusing, and it is hard to form a self identity I guess.

Again, she sees it as another tough decision:

I've been on them for a good six months now, no problems, but (pause) changing who you are is a hard choice to make, even if it is a healthy choice for you, so it comes down to... do I act like I really am? Or do I live like a functioning adult?

Dani is also uneasy with the way medication changes her moods, particularly the way it lessens "natural highs and lows." When she does not her medication, she experiences a wide range of emotions:

Off medication, I am a lot more creative than when I am when I am on it. In, like the highs I guess...I'm really active, really energetic, really bubbly, and happy and stuff (with laughter). But then in the lows, I'll just cry and not leave my room for three days.

When she takes medication, she notices a major shift:

It's weird, because ...there's got to be a certain amount of highs and lows that are natural for anybody to feel, and for me the medication takes away the natural highs and lows. I don't think anybody is supposed to be this static, single-ply emotion, but that's kind of like what the medication does.

Again, she is ambivalent. "It is really confusing, because when I am off medication it is really rocky to deal with, but when I am on them, it is too straight to be normal."

Although Dani is still uncomfortable with the way medication makes her feel, the majority of her friends and family encourage her to continue treatment. "My friends say that they can see a huge difference between me on and off (medication), and they say they prefer me on them because I am hard to deal with when I am not on them (with laughter)." She finds that she has more difficulty interacting with others when she is not taking her medication, "My boyfriend and other friends can always tell when I am off my meds because there will be nothing wrong, and then I will say something random that starts a fight." When Dani was originally diagnosed with depression, her parents expressed very different attitudes toward her taking medication, which perhaps contributed to her ambivalence:

It is kind of interesting cause when I first got on medication, when my psychiatrist thought I had clinical depression...ummm...it was always kind of like an issue with my mom, she didn't really want me to be on medication...it took her a long time to accept it.

She became very frustrated with her mother, “You don’t tell someone who is diabetic to stop taking insulin, so it isn’t a good idea to tell someone who is barely stable to stop taking her medication.” Her dad, however:

Is a lot more realistic than my mom honestly. He doesn’t like me on it because of the fact I’m on it because I am unhappy without it. Because if you are happy on them, there is no reason to decide you are better off without them, because you are not.

Currently, Dani is taking medication and recognizes how it helps her despite social, academic and personal costs:

I don’t like the idea of being on meds, but I realize how stupid it is for me personally not to be on it, cause like, I’ll be fine for two months or so, I’ll be like happy sailing, “Woohoo, I am off my meds, everything is good,” then I’ll start being really tired for two or three days and I’ll start crying everyday and having self-harming thoughts and can’t leave my room and the worst depression possible, then I will be like “wheeeee.” It is a ridiculous roller coaster. I can’t cope with it. It’s not easy....so, I take my meds...because if your illness is getting in the way of you going to classes, and having friends, and being in social situations, and stuff, you should do something about it, because it is debilitating...but yeah, it is a hard choice.

She also understands that she will:

Probably be on medication for the rest of my life. Having bipolar is not something you outgrow (pause) I can whine and mope or be like okay let’s move on past that

now...it is not going to change. There is no point in regretting you have absolutely no power in changing.

*Theme Two: Social Acceptance and Understanding.* Finding social acceptance and understanding is another challenging aspect of Dani's experience. She feels that her friends sometimes dismiss her feelings or concerns because of her EBD:

Them knowing that I have this mental disorder and take meds...they sort of discredit me, and blame things on the medications or the bipolar. For example, last weekend I spent five hours baking scones for this tea party I was throwing for my friends. Everything here is alcohol and drug based, so I wanted to throw a clean party. A lot of my friends promised they would go, and most of them missed it. Later on that weekend when I was like, "guys, you promised you would come but you didn't," they were like, "Dani, are you off your meds again, you're so touchy." So it's like they kind of use me being on or off my meds as like, umm, I guess justification for ignoring my like concerns, I guess.

Her parents have also reacted similarly:

When I was younger and kind of depressed, they (my parents) wouldn't say, "do you want to talk about it?" They would just say, "Okay, we will make you an appointment"...my boyfriend is the only one who doesn't do that...everyone else kind of uses it as "hey, you are sort of crazy, so we can be excused for whatever we do."

These reactions make Dani feel that her friends and family treat her differently than other people because she has an EBD, and that it is easy to disregard what she is saying or

feeling because of her disorder. When Dani feels dismissed or discounted, she gets “really angry” and argues with her parents and friends:

I fight with my parents some times, and I say, “You just can’t send me to some doctor and pay \$200 to take care of your kid,” and like, sometimes the most effective solution is just “what are you sad about, oh, you got a D on your test, I’m sorry.”

She regrets disclosing to one of her friends and often fights with him when he assumes that her medication is influencing her moods. “One of my best friends is a psych (stet) major, so it is kind of annoying because he is always, ‘oh, you must be off your medication.’ I retort, ‘But you must be off yours because you are being a dick (with laughter).’”

It is important to Dani that people understand that:

When you hear mental disorder you can’t just immediately discredit all their feelings and emotions because...yes, some of me being touchy about stuff is going to come from an illness, but some of it is just being human. You can’t be like, “What your feeling is invalid because you are crazy.”

In addition to feeling frustration because others often dismiss her feelings, she also expresses a need for people to understand that she does have a medical condition.

Also, it (bipolar) *is* an illness. I’m not voluntarily being depressed. I can’t just talk to someone and be better. It is a lack of serotonin in my brain; it’s not anything other than that. Would you like make fun of someone who had to take insulin, or



someone who had to like a pacemaker, no you would never do that. So why would you ever consider like treating a mental illness any other way?

She also wants people to understand that having an EBD “is hard and that they should go easy on people (who have an EBD)...there is no reason to be a jerk.”

*Theme Three: Establishing and Maintaining Support Systems.* Dani finds it difficult to ask for support because:

Asking for help admits weaknesses I guess...Being the strong one in the family has always been my best point because my sister is a huge overachiever...the golden child...It's been hard to ask for help because I'm not the best with grades, I'm not the prettiest or the smartest or not the best at anything, so if you could say someone is the best at being stoic...that's me. So asking for help is hard because it is admitting another weakness.

She is sometimes reluctant to seek assistance because she is concerned about how her friends and family will react:

I always feel like people are going to yell at me if I am off my meds because people have yelled at me in the past. And I'm like, “I am *trying*; I am too old to have people yell at me.” So sometimes there have been times when I felt so desperately out of control with everything, but I couldn't like explain to anybody why I was so freaking out about everything, because I stopped seeing counselors, and couldn't get the meds, then I have to go back (to counseling), then explain why I went off my meds...and I'm like, “I don't know, I wanted too.”

She describes these situations as being “stuck in a horrible hole” and feels like she has to “justify my decisions when...I just need get back on (medication) again.” She often tries to “wean” herself off of medication and doesn’t tell her therapist. However, she recently realized that she needs to follow the prescribed dosage. “This year I was finally just honest with my therapist...I’m taking a low dose, can you help me out? And he was like yeah, and I went back to the psychiatrist.”

Although she finds it difficult to ask for assistance, Dani has established formal and informal support systems that help her. In addition to taking medication, she sees a psychologist on a regular basis:

The therapy is kind of hard because I’ve never had a therapist who tells me how to fix my problems, but the one I’m seeing now, he’s really good. It’s just really nice to know I’m not doing everything wrong and he is good at reassuring me...and it is really good to have someone who really knows you check up on you.

She finds that therapy and medication help her during her transition from adolescence to adulthood, particularly during college:

I guess it helped me a lot because there have been a couple of times where I’ve been like “I can’t do this,” and whoever I’m seeing at the time ends up telling me, “Yeah you can, stick it out, get your meds stabilized and you’ll be okay and you can make it through this.”

She has also disclosed having an EBD to professors when she was struggling:

My professors did know one semester, because umm...my medication...it was just really a bad semester, because this terrible ex-boyfriend, he was using my credit cards and stuff, so I didn't have money to pay for my meds, and I was terrified to tell my parents about it because I knew they would be mad at me for being stupid. I ended up telling them later, but it got to the point where like I could not deal with anything, and so I went and told a couple of my professors, and said, "I am not trying to ignore your classes, I am just trying to get out of this horrible relationship. I am off my meds, I can't afford it. I am not ignoring you; I am just trying to get myself out of this hole right now." And they were like, "Okay, thank you for keeping us updated, we understand." I was worried about passing that semester, but they really understood and that helped."

In addition to seeking assistance from mental health services and her professors, she also has developed a support system of friends. "Having friends who support me doing this is helpful. It is nice to have a group of friends who I hang out with that being happy is cool instead of like being sad and drawing little eye liner tears on your face and stuff." Her boyfriend is also very supportive, and is the person she identifies as being the most helpful to her:

Whenever I am stressed about something I can talk to him about it...for example, this summer I was just trying to decide whether or not I should go back on my meds or whatever, and I had a four hour conversation with my boyfriend weighing the pros and cons. It was nice because instead of just telling me to go

back on them, like everyone else does, he said, “You are like this when you are on and like this when you are off” and we came up with four pages of lists.

She finds that a positive support group that she trusts assists her during the transition process:

I guess the whole thing with some of my friends, the ones that actually know, it is kind of helpful, because they will be like, “Hey come out and hang out with us” and if I say I don’t want to, they will ask and say, “Is it because you don’t want to or is it because you are feeling anxious? Just come and stick by me and you can still be social and have fun.” If you have people you trust, it’s just helpful to have them around to help you figure out what you need help with I guess.

She discloses having an EBD with close friends because:

If I see my friends everyday, if they don’t know I have this illness, or on meds, none of them are going to understand, they are going to think “she’s mad at us.” But I’ve had friends say “I am really worried about you, are you okay, or are you off your meds?” Just the fact that other people are able to notice it, makes me realize that it (medication) has changed my mood enough that I should go back on them. So I mean I figure if someone knows me well enough to notice a mood change they probably know I am on meds.

*Theme Four: Developing Coping and Management Strategies.* In addition to establishing and maintaining a positive support system, Dani has also developed strategies and coping mechanisms to help her manage her bipolar disorder. “What I always do is take pride in being able to take care of myself. For example, I applied to

college and was accepted before my parents even asked me about it...I just try to take care of things.” She also researches information about bipolar and ways to cope. “It’s so funny because he (her therapist) suggests things to me that I am already doing. I do the research, I figure life’s rough enough if you go in blind.” When stressed or anxious, she finds ways to relax, “Sometimes I’ll go on a long walk, just relax and hang out in my room and watch a movie. I often cook to relieve stress. I like making fancy meals.”

Dani also utilizes self-regulation to monitor her moods and medication. She describes herself as being in a constant state of “awareness” of her mind and her medication. She monitors the amount of sleep she gets, her diet, and her moods:

I guess one of the biggest things for me is trying to determine whether or not my meds are doing me good at the moment. It’s like, “Okay, I feel weird, is this because I am stressed and I have to write a paper and not getting sleep and having arguments, or is it the medication?” (I am) always trying to figure out what is really happening.

At these times, she “experiments” by trying different things such as resting more, changing her diet, or talking to her friends. If these steps do not work she consults her therapist. “If I still feel weird, then I will talk to my therapist, ‘I don’t know what’s going on...I tried this and nothing helped.’ But if all of my moods go back to normal when I get sleep, I know it’s not the meds, but me overworking.”

Although she expresses frustration regarding her EBD, Dani also takes pride in her successes. Her greatest achievement, so far, is “The fact that I’ve never failed a class. That’s kind of exciting because...there have been a couple of times when I didn’t think I

would pass (with laughter).” She is self motivated and “determined” to be successful and achieve her goals. “I don’t want to be unhappy. So if you don’t want something or you do want something...it makes it a lot easier to pursue it and go after it.” She believes that being happy is a choice:

You can decide “I am going to be happy” in the end. It’s kind of like if someone tells you long enough you are stupid you are going to start believing but you can go for the opposite of that. You have to tell yourself “I can be happy; I can do this.” But if you go through it labeling yourself, “I’m depressed,” then you are always going to feel like you have to like follow the standard of being depressed.

While she believes that she can determine her happiness, she views seeking assistance as part of the process:

I had to realize that it is the equivalent of heart medication or like insulin or whatever, and realize it is not me admitting I’m crazy. It is me fixing a problem. You can’t just work out and lower your blood pressure...you can’t work out and not have a brain disorder.

### *Impressions*

Dani’s transition experience can be understood in a variety of ways. Some underlying structures that permeate her experience include the impact of EBD and treatment on her life, the way she perceives herself, and her relations with others. These constructions are imbued with ambivalence, particularly as she struggles with having to make choices regarding her treatment.

*Impact of EBD and Treatment.* Both the symptoms of her EBD and the perceived cost of her EBD, particularly as it relates to treatment, impact Dani's transition from adolescence to adulthood. She must actively manage and monitor her mood swings and emotions. When she does not take medication, or when it is not stabilized, she experiences "low streaks," depression, and performs poorly in her coursework.

She finds that treatment, in the form of medication and therapy, helps but causes confusion and comes with a cost to her identity and her social life. She sometimes wonders if being on medication changes who she is, and that she has to make a choice to "be a functioning adult" or "act like I really am." She also questions "who she really is," asking herself if the real Dani is the "medicated one," or the "crazy" one, an idea she finds "scary" and confusing. She also feels that she must choose between her health and fitting in socially because so many of her friends drink and take drugs. She sometimes feels left out and isolated because she is on medication and cannot "party" with her friends.

Although she perceives that taking medication comes at a high price, treatment is a necessary element to her success. She believes that her life is "much worse when she is not on treatment" because of the EBD.

*Self Perception and Identity.* As previously discussed, Dani is still coming to terms with her identity, particularly as it is affected by having an EBD. She questions the diagnosis of bipolar because she does not fit her conception of this disorder. She also feels different than other people, and believes that her life is more difficult than for people who do not have an EBD.

Despite her ambivalence regarding her identity, Dani has a definite sense of self. She describes herself as strong and stubborn, someone who is capable of managing the stressors in her life, with the assistance and support from others. However, she sometimes does not want to ask for help because she does not want to be considered weak. She is beginning to be comfortable with seeking assistance, because she knows it does help her, and she believes that she can be happy through her own determination combined with treatment.

It also helps her to know that she is not “crazy” and that her mood swings are due to a chemical imbalance rather than something innately wrong with her. She often uses medical metaphors (e.g., diabetes, high blood pressure) when discussing her EBD, and it is important for her that friends and family see her disorder is viewed as a chemical imbalance and medical issue. Dani is comfortable defending herself when people question if medication is necessary:

You know, I’ve had people be like, “People in this country are overmedicated,” and I’m like, “That’s your choice, but I tried to kill myself when I was younger and off meds, so you make the call if people are overmedicated, but I’m not.”

Although a few people have questioned her diagnosis, she rarely regrets disclosing her EBD, and finds that most people are supportive.

*Relations with Others.* Dani’s self perception is closely related to her interactions and relations with others. The reactions of other people influence the way she sees herself and her decisions regarding treatment. “When people can notice that you are not on medication and are acting crazy, then you realize that something is going on.” It is



important for her that others understand she has a medical condition, rather than just being moody or “crazy.” In the past, she has also avoided treatment or not admitted that she went off medication because she is afraid of other people’s reactions. She also experiences frustration and anger when people dismiss her feelings and thoughts because of her EBD or because she is on medication.

Although she wants her friends to validate her feelings, rather than dismissing them because of her bipolar disorder, she wants them to recognize the challenges of her EBD. Having people know and understand what she is going through is pivotal to her success. She describes having trustworthy friends who are happy and positive as integral to her happiness and emotional stability. She uses words such as reassurance, empathy, understanding and acceptance (from others) when asked what is the most helpful to her during her transition from adolescence to adulthood.

### *Beth*

Beth, a 24-year-old African American female, attends school full time to pursue a B.A. in Psychology, and returns to her home town during the holidays and summers to work at a local hospital she has worked at for years, “When I was accepted here, they (the hospital administration) didn’t want to let me go. So they did this thing where I’m seasonal, where I just come for holidays and when I have time off.” She is also a senator in student government, and the president of a group she started for students with disabilities. Her coursework has been challenging for her and she sighed when she stated she was “very excited to graduate...just one more year (with laughter).” She maintained

an enthusiastic and positive demeanor throughout the interview, and answered questions carefully and thoughtfully.

Beth was waiting at the coffee shop when I arrived and stated that she was eager to participate in the interview because she “hopes people can benefit from her experience.” Both her enthusiasm and engaging smile were infectious throughout the interview, and she interspersed her responses with laughter or sighs. She also used a variety of non-verbal responses such as hand gestures, shaking her head, and widening her eyes to reinforce her points. Throughout the interview, she appeared comfortable and confident, even though we were in a public place. When asked if she would like to move to a more private setting, she said she was fine and is comfortable sharing her story with “whoever wants to hear it.”

She was diagnosed with Generalized Anxiety Disorder (GAD) when she was “22 or 23”, but was experiencing anxiety for “years and had no idea.” High school was easy for Beth, but she had difficulty taking college entrance exams “I had to take them (SAT and ACT) four or five times and would be sick the week before and stressing about it; I took them both four or five times and still couldn’t get the grade I wanted.” She then decided to attend community college near her home. The summer before she left to attend a four-year university to complete her degree was difficult:

Everything was going wrong for me, in every possible way. I had just broken up with my boyfriend. I had broken up with my best friend of six, seven years. Some (other) things bad happened (pause) and it was just devastating to me. I found out at the last moment that I wouldn’t be graduating (community college) because I

was one credit short due to a technicality. So all of that (occurred), and I stayed in bed for two months.

Her anxiety continued after the move:

Before (college) I didn't care about exams, I always passed, but now it's a huge thing where it takes a toll on my self-esteem, and I would struggle and wouldn't sleep. And I remember before I went for help I could not sleep for four months...for *four months straight*, I could not sleep.

Beth went to several doctors for multiple symptoms, including insomnia, indigestion, and the flu. She was prescribed numerous medications for the variety of symptoms. Tiring of the different medications and advice, she determined that her symptoms were related to test anxiety so went to the school Counseling and Wellness center<sup>15</sup> to learn study skills and test taking strategies.

During the meeting, the counselor suggested Beth see a doctor, which "was a surprise because I'm thinking I just need help take tests or exams." However, the counselor reiterated that she should come back to meet with a doctor. When she returned to the center, her appointment was with a psychiatrist, which "shocked" her:

I'm thinking what is going on here, and he had all my information and the notes, and everything she had taken before and he said you have *GAD and I am thinking this is happening* (eyes widened for emphasis). And I am dumfounded and can't believe this is happening.

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<sup>15</sup> The Counseling and Wellness center serves students at the independent honors college that Lisa and Dani attend and this branch campus

Beth was also surprised because the counselor did not indicate she was referring her to a psychiatrist, “I thought it was just another specialist...because I had gone to so many doctors for my health problems.” Her primary physician put her on “four or five drugs for physical symptoms, but I guess he didn’t know enough to acknowledge the GAD.” She has mixed feelings regarding her diagnosis:

I was actually relieved that it just wasn’t me, and they had a name for it. But at the same time, now I am labeled. And I am now I’m a disability, or I’m on the disability list, I didn’t like that. So (I) take one day at a time.

She then began a series of medications, including Lexapro,<sup>16</sup> Ambien,<sup>17</sup> Xanax,<sup>18</sup> and a “couple of others I can’t remember (with laughter)”. She says the Lexapro helped but she stopped taking it because it gave her stomach cramps. She is no longer taking medication, “I don’t even remember how many (different kinds) I’ve taken, and they don’t work. So I decided to give up on it. I struggle through. I go to school, and do what I have to do, but everyday is a struggle.”

She is on track to graduate this summer with a B.A. in Psychology, and plans to move back to her home town and become a social worker at the hospital where she is currently employed, “they already have my schedule; they are always calling me.” Beth believes that her EBD has impacted her professional goals. She is considering a future

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<sup>16</sup> Lexapro is an SSRI used to treat depression and anxiety. Its generic equivalent is escitalopram.

<sup>17</sup> Ambien is a sedative-type drug that helps to relieve insomnia. Its generic equivalent is Zolpidem.

<sup>18</sup> Xanax is a psychotropic medication used to treat anxiety and panic disorders. Its generic equivalent is alprazolam.

career as a Physicians' Assistant or doctor, but wonders if the additional years required for a medical degree would be too much:

I'm always in between medical school (or a P.A. program), (med school) is four years plus residency whereas P.A. is only two years, and I am thinking those last two years I can be free of school. I want to be out of school (with laughter).

Sometimes, I think about giving up completely, and try to think of other alternatives. I'm over it. I don't enjoy it. It's like a big hassle and a nuisance and everything on my body. It is just a lot.

Although school is difficult for her, she is still determined to pursue a career in medicine, and plans to take courses while she is working at the hospital, "I'm not gonna stop now. If I stop now, I'll hate it."

#### *Analysis of Beth's Experience*

As previously stated, Beth began to experience symptoms of anxiety when she began the transition from high school to college:

High school was easy. It was pretty easy and very restricted. I was still a child, college makes you grow. You feel like you are an adult and trying to take your future into your hands, and this really means something.

She views success in college as directly related to success in life:

You know everybody can have their high school degree; it is free. This one you have to work for if you don't have scholarships, and this is getting ready for the real world. So if I can't take care of college, what am I supposed to do for the rest of my life?

Her description of her transition experience reveals five core themes that have impacted her ability to achieve her goals: 1) Personal and academic challenges related to anxiety; 2) Impact of EBD on self-perception and perception of others; 3) Assistance and support; 4) Developing Coping and Management Strategies; and, 5) Concern for others.

*Theme One: Academic and Personal Challenges Related to Anxiety.* Having Generalized Anxiety Disorder (GAD) has impacted Beth both academically and personally. In fact, Beth's narrative underscored how her anxiety is something she must deal with regularly. "(I have) to think about this everyday. It is a hassle; I don't like it." Although she sought help for test anxiety, she experiences physical and emotional distress during other classroom situations as well. In addition to academic situations, Beth has experienced panic attacks in social situations, or in any situation in which she feels trapped or "closed in."

Taking exams are particularly difficult for Beth:

If I'm taking exams, I get so much anxiety. I can study so hard, but when it comes time to take it, I forget everything. I can teach other people but then I forget how to do it myself. Or I cannot even see what's on the exam anymore. I can't see the words. I can't pay attention. Frequently, I keep getting up to go to the bathroom because I have to use the bathroom and I have stomach cramps and my stomach is making noises and that is so embarrassing to me, so I am constantly getting up, so then it looks like I am cheating. And, of course, I didn't have a name for it but I couldn't just tell the teacher I have stomach cramps. Who is going to believe that?

She described her anxiety over testing as a cycle, “I would then fail the exam and get depressed, and then it takes a week to get back the test and then I am worried about the next one. I am sick before and sick afterwards.” She often does not look at the exam grade because of her nervousness regarding the outcome:

Actually, I’m just scared. So I don’t want to check, what’s the point? It’s better not to look at it, and just keep doing what I have to do. It was just a fear thing, to avoid reality. Of course, I have to check before drop deadline. Usually people want to check right away, but I won’t (with laughter).

She now receives accommodations which allow her to take exams in a private setting, which helps because she no longer has to worry about disrupting other students or becoming embarrassed. However, she still struggles with anxiety regarding her performance. She did say it is getting better; she had taken a chemistry test the day before the interview and she said “I am not worried about it; it’s weird not to be so stressed about it.” When asked why she wasn’t concerned about this test, she answered with a laugh and a bright smile, “Because I checked Blackboard and saw that I have an A in the class – an *A* (with laughter). So I know I am definitely going to pass.”

Beth also experiences anxiety regarding the classroom setting itself:

When I go to class, if the classroom is too small, or people sit too close to me or if it is very quiet, my stomach will start making noises and I get really embarrassed and that is all I am thinking about and I am sweating, and my heart will start to race. This just happened to me Tuesday (with a sigh).

She describes the classroom as a continual “obstacle,” and she is “stressed out” before the semester begins. “Sometimes I’ll go before the semester even starts so I can see how big they are and how they are arranged, so I can get my comfort level.” When she is not comfortable, she is unable to concentrate and often has to leave;

I don’t hear what the teacher is saying anymore; I don’t care. I’ll try to pay attention, but my hands will shake, and will be extremely sweaty and I can hear and feel my heart racing and my head is pounding, and I am just waiting for the big breakout of my stomach making noises and embarrassing me in class. And that is all I hear and think about. And I am just looking at that door, thinking “Should I leave?” And I am fighting myself, “Should I stay?” And I end up leaving. Tuesday was a bad day because I had to get up two or three times. Sometimes I just have to get up once and be okay. Sometimes I leave and don’t come back. On Tuesday, I fought through it, but when class was *finally* over, I ran home and went to bed for the rest of the day. I was really depressed. So, it is a lot to handle, and I try not to think about it because that’s all you can do because I’m thinking if I’m sitting here and close to the door, and I won’t get so nervous and my stomach make noises.

She does not experience anxiety in all of her classes, and says it “depends on the situation.” For example, her science class is large and “like the theatre so I am able to spread out...there are not a lot of people and they don’t surround you. It is okay, and I do not have to get up.” Smaller classrooms are much more difficult for her. “My psych (stet) class is four hours long and is in a very small classroom. You have no choice but to sit



with other people. And the tables are very close together and it's very uncomfortable (pause) it freaks me out." Beth often begins to feel anxious before class begins:

This Tuesday, I woke up with some anxiety, and I was like "Oh no," but I made myself go because I don't want to miss class. Driving there, I sat in the car five-ten minutes, and I said "what the heck, I am here." (It was) 20 to 30 minutes in the class and I couldn't do it. I wrote her a note and apologized, I am getting an anxiety attack. This is the professor that I am not her favorite.

Because most of the classrooms in the college she attends are small, she frequently encounters this problem. "And I'm thinking how am I going to do next semester at (the university), I don't have a chance to have a huge classroom even more. I am already thinking about that."

Before Beth went to the student disability services office and starting receiving accommodations, she was struggling academically:

It was bad. I was failing everything, and I know my study habits were not well ... but the anxiety did hurt me because I could not pay attention in class or I would not show up when I was severely depressed. I messed up my GPA with an F and two W's. That F messed me up (with a sigh).

Although the student disability services office staff has helped her and she knows "how to deal with things better," her anxiety is something she "lives with...I'm always scared, always nervous, but it is normal to me now."

Although most of her anxiety is related to school, she has also experienced panic attacks at home, and says that her anxiety is sometimes worse at home:

Actually, I have it (anxiety) more. Umm (pause) if I'm severely stressed or whatever, there was one time, probably three weeks ago, I woke up with a panic attack. It wakes me up sometimes and I thought I was going to die. I didn't know what to do; it was 3 am and I didn't go back to sleep until 7 am.

She has also felt anxious with other people, particularly if she is "stressed emotionally" or feeling "trapped:"

This summer I had a panic attack on a road trip with my family, and I tried to hide it but it didn't work because my sister saw me crying and I think it was because we were driving from Miami to Orlando and there were the three of us in the back seat, and I'm in the middle, and I was fine the whole time until I was on my way home and that's when it started. I sat there and took it the whole time. And they did not stop. My sister saw me crying and said, "What in the world is wrong with you?" and she said "here" and gave me some music. That really helped; I just listened to it and closed my eyes, and when we arrived at my parents', I took my car and drove straight home...they all called me on my way home, but I couldn't talk about it, I didn't know what was wrong.

*Theme Two: Impact of EBD on Self-Perception and Perception of Others.* Beth feels ambivalence regarding her diagnosis of GAD. "I am relieved that I finally have something to put together that makes sense, and that I'm not the only one out there. But on the other hand, I'm disabled." When asked to explain what "disabled" means to her, she responded:

Disabled (pause) not able to take care of myself or I am labeled. When I think of disabled I think of someone who is really severely disabled, but I never would have put this under the category, but I am. I don't like it, maybe because I am independent and I care for myself. I do things for myself and I love to do things for others, and to have something that makes me feel lower doesn't help me, but I accept it.

Although she "accepts it," she is still uncomfortable being labeled:

I am labeled, that's number one. I don't like to categorize myself and I never said I have GAD, I may say I have an anxiety disorder. (It's the) same thing, but I never say GAD for some reason (pause) I don't know why.

However, she recognizes the benefits of her diagnosis, "I am happy there is a name for it" because it is easier to explain to her professors why she needs to leave the room so frequently "Before I couldn't say my stomach hurts, and I get dizzy. Anyone can get dizzy. Now that I have it I can say this is what's happening and why."

She also has trouble expressing that she feels anxious or uncomfortable:

My problem is I kept everything in. That's another thing. I'll keep everything inside. I'll sit in front of you and you won't even know I am having an attack. I can hold it that well. I may breathe a few times, but you won't know I am having an attack.

When this occurs, she leaves the situation and is then "fine." She also puts a lot of pressure on herself to succeed, "I get mad if stuff doesn't go my way; I am really hard on

myself. By the time I am so worked up I have to leave, I am depressed and am angry at myself.”

Beth is also concerned about the way her professors perceive her:

Some professors are great, but others become frustrated. Right now, that Tuesday class is so difficult so I leave a lot. One time, I left and didn't go back for 20 -25 minutes. And I call her to apologize or explain. And she says, “We do have help.” And I say “I know; I am not on meds anymore and I don't want to be.” And...I don't know; I know I am not the teacher's favorite. She knows I have anxiety but she is very strict with her class. So I am probably a nuisance to her and I apologize all the time.

Beth is also concerned that professors may think she is cheating, particularly before she was identified and started receiving testing accommodations:

Back in (her home town), I didn't know what it was. Now that I know I wish I had known to tell her because she thought I was cheating on my exams. You know you can just have a face a look, and I tried to tell her to have a nice day, and she just walked off, and I'm like “Wow, I studied my butt off and passed the exam and this is what I get.” But I didn't know what I have, so I would constantly get up. And it does look like cheating, but it wasn't. She didn't penalize me but you could tell she thought I was. And I told her I get nervous, but it didn't make a difference. That actually bothered me for two or three weeks. And it bothered me that she would that that of me because I was always good in her class and participate and did my homework and passed my exams. Also, I had to apologize

to her because I did not show up Monday or Wednesday, and I just showed up on Friday.

Beth also wonders if many people take anxiety disorder seriously:

Some people might not take it seriously because anyone can say their depressed; that's an easy out. Me, I'm just a little different because mine is severe because I am physically in pain. A lot of people don't take it seriously; my father didn't take it seriously until he actually saw me break down and said this is real, so he bought me a book (with laughter). Maybe my peers don't take it seriously. In the professional world, I do think they do, especially my professors. They see I am not coming to class or am getting up or might see that I can't do this anymore, and they understand, especially if I'm in an emotional state and I'm trying to explain, they see this is something serious. I guess it depends on the person.

Although Beth is admittedly hard on herself and worries about the perceptions of others, she does recognize her accomplishments. "I know I am persistent. I could have given up and my counselor made me aware that I could have went to drugs, alcohol, instead I went for help. I don't drink or smoke." One aspect of Beth's life where she does not feel anxious is at the hospital where she works, "I am active there, it is hands on...they love me there and they keep calling me asking me when I'm going to come back."

### *Theme Three: Assistance and Support*

Beth has sought and utilized a variety of assistance and support since she has been diagnosed with GAD, including testing accommodations through the Office of Student

Disability Services, medication, study skills workshops, and counseling. The director of SDS also emails her professors to let them know about Beth's EBD and her need for testing accommodations. She is currently utilizing the SDS accommodations and the strategies she learned from the workshops, opting to stop taking medication or attend counseling. She did wait until her junior year of college, thinking she just needed to "try a little harder." However, she did seek medical treatment for migraines and stomach cramps, but that brought her little relief.

She finally decided to go to the counseling setting for help with her testing anxiety because she was "afraid of failing out." She assumed they would give her tips and perhaps extended time on her tests. At that time, she was referred to a psychiatrist and psychologist for anxiety, and was prescribed Lexapro:

The Lexapro worked actually. There was one time I was taking an exam and I was okay; it also lessened the migraines, but it made me sick all the time. And I said "I'll take it," but he (the psychiatrist) said, "No you can't be on this if it makes you uncomfortable" and he made me stop. He then tried other things but they just didn't work at all. It was all trial and error.

She was originally "excited" to take medication because she thought it "would work."

However:

The only thing I didn't like was that he said "it will help you but it will not cure it, you will have to take this the rest of your life to maintain it," and I didn't like that at all. *To be on meds for the rest of your life to maintain something?* I don't want to be like that at all. I am not comfortable with it. What are the side effects? At the

time I was only 22, I have a long way to go to tell me every single day of my life I have to pop a pill to be normal? No. If it worked maybe (with laughter) but I don't know.

She also attended counseling for a brief time, which did:

Bring things to light. It helped me see what I think, and why it is happening and all that good stuff (with laughter). I'm also too hard on myself...I always have huge goals and if I don't get it, I put myself down. Everybody's their own critic, but she made me see the light, she said "you are not a drug addict, you are not an alcoholic, you are not selling yourself short; you are not being promiscuous or anything. You are doing what you have to do and you are persistent." Usually people have to tell me good stuff about myself because I don't see it. So she made me write it down, and it helps to actually see it on paper.

Beth decided to stop seeing a counselor once her therapist left because she didn't "feel comfortable going to somebody else to start all over again." Also, she believes she has:

A handle on it. I don't see where else someone can help me. Honestly. If anything, they will just try to feed me meds again. Or try to get me to develop my feelings. Is that going to do any good? Am I still going to have panic attacks, and school will still be hard.

Beth also attended a study skills workshop at a local community college, which:

Helped a lot. He (the instructor) had a whole booklet that told me the things that I was doing wrong. And it made sense. I learned the right ways to study, and when and where I should study. I used to study in my bedroom, which just made it

harder to sleep at night. Now I study at the library or in the dining room. I also learned how to pace myself. It helped. I am getting an A in chemistry for the first time. I thought it was a mistake. I am very happy about that (with a smile and laughter).

Beth has learned that disclosing her EBD to her professors is very beneficial.

“They get a letter from the director of the disabilities office, so it makes it easier to tell them, but they don’t understand how serious it is until I explain it in more detail.” She feels fortunate because she has had understanding and helpful professors:

When you do tell them they work with you. If you don’t, they don’t know, and you don’t give them the chance to help you, and I’ve learned that. I’ve had two professors that were ridiculously nice. They went out of their way. Last time I took the Calculus I couldn’t see in her class. There were too many people, all close together. I tried twice and I couldn’t do it. I got up and didn’t show up. She called me to find out what was wrong with me or if everything was okay. And I explained to her what I had and could not sit in the class because I was uncomfortable and could not pay attention to what she was saying. And then she told me I didn’t have to come to class and she taught me the course in her office, and she let me do all the homework. She did that the whole semester with me. She made me drop the class, but still continued that way if I passed the last one she would reinstate me. That was the nicest (thing to do) and I will never forget her for that.



Beth believes that the assistance she has received has made her college experience:

Much better...I'm more comfortable. It is not as stressful, where I'm not thinking I am going to the classroom taking the exams. I go straight to the testing center, and they give me my own room. So I am very comfortable, pleased, relieved about it and it is showing in my exam scores.

She credits all the support she has received for helping her reach her academic goals. When asked what has been the most helpful, she responded "I guess it is a variety of a lot of things. A little bit of everything...the counseling helped...the workshop helped...my parents support me...it is a community thing."

*Theme Four: Coping and Management Strategies.* Beth has developed numerous coping and management strategies to help her accomplish her goals. She recognizes she will "never be cured" and that managing her anxiety is a "daily thing, something I always think about." Her strategies are mostly positive, such as practicing "better" study habits, focusing on her goals, relieving stress through breathing exercises, praying, going to the gym, and getting involved in the community. As previously mentioned, Beth learned better study habits from a study skills workshop. In addition to studying at the library or dining room, she also completes her homework diligently. "I didn't use to do the homework, especially in science classes. I also read the chapter before and after class, and write things down." She also has learned to manage her time, so she can take breaks when reading or studying. Beth finds focusing on her goals a major source of strength:

My counselor would tell me to write things down about my goals and what I want... actually I have a little motivational card. It's a little index card and I'm supposed to put everything I want towards the end after finishing my educational career. It has a sign of being a physician, a stethoscope, shows a big house and the beach and travelling. So it is always there so when I'm like I don't want this, it (her motivation card) is right there in my face.

She has also developed coping strategies to deal with panic attacks and insomnia. "I do breathing exercises, and I received CDs to help me, sometimes those help. You listen to them asleep. I also try to think about what causes the stress, trace it back, so I can deal with it." She also finds that praying and reading the Bible can also relieve stress "I pray and read my bible... sometimes I'll read passages depending on what situation I'm in. I'll recite Psalm 23. It helps."

Throughout the interview, Beth discussed how helpful exercise is, and recommends it to "anyone who feels stress; it takes away the aggression." "Exercising really relieves stress, and I have so much tension in neck and shoulders, it's ridiculous, so exercising helps. It feels good when you go to the gym." She has also found that getting involved in other activities is beneficial:

Jane, the SDS director, has helped me so much though, getting me involved. I am senator at SG (student government), and I am the president of a group, I am supposed to be a mentor, but with my schedule, it becomes too much.

She believes that helping others is a way to release some of her anxiety because it:

Takes the focus off...I want to help people though. But anything, with depression, when I came out here, I didn't know one soul. So it's just easy to run back home. That's how it starts. You segregate yourself from everybody and everything. But now, I am more involved, and that really helps. I am doing so much now. I am doing missionary work and travelling with the student government.

Beth learned many of her coping strategies from her counselor and workshop instructor; however, she continues to read and develop her own strategies:

I am always listening and taking notes, even when watching television (with laughter). I take notes everywhere. It would help if I knew more techniques, but there is only so much you can do until it's offered. Now I am reading a book about how to manage anxiety without medication...exercise, eating right, vitamins, etc. My father bought it for me. I am always looking for techniques on how to lessen anxiety or how to deal with it. That's how I get help.

*Theme Five: Concern for Others.* Beth mainly relies on herself to manage her GAD because she does not want to "burden" her friends and family. She knows they care about her but her parents are:

Worriers... they are always calling me, and get scared if something happens, and tell me to "Calm down, it's okay." This summer, I broke down in front of my father, and he broke down because he had no idea (how bad her anxiety is) until I was having a panic attack, and he came in the middle of it and to see how he was hurting for me because I live out here by myself and now they are worried. I was

angry with myself because he saw me like that, and now they are worried all the time. But I have to live with it.

She finds little comfort in sharing her experience with her family because “it makes them worry.” She tells her friends or family about her panic attacks if they are going through something and she thinks it will help them:

If something happens to them, I’ll give an example of myself. I won’t tell them about my problems, especially since I’m here by myself, I don’t want to stress them. I am always protecting them... My mom actually had a panic attack herself. She didn’t know what she had, and I told her that I had them, and I just had one. “Oh god, my baby, you are always sick, I am going to pray for you”...so I don’t share too much.

She is also careful not to share too much with her friends:

My best friend she knows about it but I don’t talk to her about it because she tries to make me move back because everybody’s worried. I live out here by myself. I don’t tell her as much, but she always gets upset with the things I tell her. So I don’t tell them about the huge panic attacks.

Beth understands that her family and friends love her and support her but she worries about them, “My parents support me, but at the same time I am protecting them and I always put other people ahead; that is just my nature.”

### *Impressions*

Beth is proud of her accomplishments and that she is going to graduate this summer; however, she is quick to point out that she is not “cured” or free from anxiety.

“It’s not like I overcame it. I still suffer from it; even today I had an attack. But what can you do? I go to the gym; it feels good when you go to the gym. I find ways to manage.”

Beth’s transition experience can be understood in various ways. Some of the structures that underlie her experience include the relationship between her academic performance and self-esteem, her continued focus on her goals and accomplishments, and her desire to please and help other people.

*Relationship between School and Self-Esteem.* Much of Beth’s anxiety appears to stem from the amount of pressure she puts on herself. When she fails an exam or has to leave class early, she becomes “severely depressed, which makes me think about my self-esteem which is wrapped up in school, and that’s what makes me nervous and that is what makes me sick.” She feels that she must achieve success in school in order to be successful in life and achieve her dream of working in medicine. She says that no one else pressures her, and that she is the one that gets “angry and mad” if she fails:

I’m testing my ability to learn, my self- esteem is incorporated with it and my intelligence. If I don’t pass my tests, I am stupid, and I would call myself stupid.

It has been hard, being an A student in high school and then coming here and barely passing. It was really hard. My GPA is low, so I am trying to work on that.

She admits that she is “too hard” on herself, and that she has “huge goals and if I don’t get it, I put myself down.” Conversely, she is able to recognize her successes, such as her current A in Chemistry.

*Importance of Goal Setting and Recognizing Accomplishments.* Although Beth struggles with GAD and is admittedly too hard on herself, she is driven by her goals and

is able to acknowledge her accomplishments. Beth has had the desire to work in the medical profession “ever since I could remember.” Although she has adjusted her goal from being a surgeon to perhaps becoming a physician’s assistant, she is determined to work in the medical field. Her motivation card has a picture of a stethoscope and lab coat on it. When asked why she has remained in college and still working on her goals she responded:

Drive, persistence, and I keep thinking if there is anything else I like to do. I can do hair, but I don’t enjoy doing it. I don’t see anything except to be a party planner, so that is just a way to get out of school, to be a copout.

She also continues to work at a hospital, where she feels valued and appreciated. “They love me there, and I love it there too.”

Beth said it has only been recently that she could acknowledge her accomplishments and her achievements:

I am my own worst critic but I am beginning to see the positives. I’m improving my grades (pause) and hey, I am still in school and I didn’t run off and cut off all my hair (smiling). *I’m still in school and have an A in Chemistry.* That’s my biggest achievement. I was screaming calling everyone, “I have an A” (with laughter).

She also travelled overseas to study abroad in Italy:

It was great; I am happy I did it. I almost didn’t do it because of this, the anxiety. I feared the classrooms, how big there were going to be. But I was like I can’t miss

out on this. But the professors were great...I don't think I would have done it before.

Her ability to recognize her own successes helps motivate her when she is feeling anxiety and stress.

*Desire to Please and Help Others.* Beth is also driven by a desire to please and help others, particularly her parents. "They look forward to seeing me in the white coat and I am afraid to disappoint them." She feels a lot of pressure "not to let other people down." She also doesn't want to disappoint her professors and finds herself "apologizing all the time." She has apologized through emails, phone calls, written notes, and face to face when she misses class, leaves early, or leaves several times during class. She feels the need to apologize because she feels like a "nuisance" and doesn't want them to think "badly of her."

Her desire to please others also helps her accomplish things she wouldn't otherwise do. For example, her mother was graduating and the family asked Beth to host the party and give a speech:

I was sick, I didn't sleep, and even up until the last minute I was trying to get out of it, and my sister was like "don't you dare, we don't have anybody (else), but it turned out great and my sister said "no one could tell you were so nervous"...but I did it because it was for my mom. I don't like to let people down. And now I am so proud of myself for doing it. I was so happy.

Beth also aspires to help other people and feels that her experiences may give her an understanding others may not have:

I believe everything happens for a reason, so I am being trained in order to help somebody else. That's how I see it. Usually those who help others have been through the same thing, and they don't want anyone else to go through it, or at least want to help them be comfortable with it. That is why I was very happy to do this with you. So that's my little step of doing it. I'll tell my story to anyone who wants to hear it; you never know who can benefit from it. If I can help other people, that would be great.

*Tara*

Tara is a pretty, 18 -year old Caucasian female with long light auburn hair, light brown eyes, and enthusiastic smile. She is an honors student and is pursuing a double major in Psychology and Communicative Science Disorders. She ultimately plans to be an audiologist. We began the interview in a public area of the library, but moved to a private room due to the distractions and the participant's discomfort. During the interview, she talked rapidly and gestured frequently to emphasize her statements. At times, she appeared nervous or uncomfortable, answering questions abruptly. Overall, her responses were measured and careful.

Tara was diagnosed with mild depression when she was 14 years old, but she first remembers feeling sad and "really, really depressed" when she was 9 years old, when her grandfather died:

I was like the closest with him (pause) and I remember that, I just couldn't understand, because I remember when he was sick. I would pray every night, "God please make him better" and it was the first time I ever had questions about



God and why he (her grandfather) died if I prayed to God. I just didn't understand it. It was just a tough experience too so it kind of hit me at the same time.

Tara's mother took her to the psychiatrist when she was 14 because she discovered cutting marks on Tara's arms:

It was funny because I was trying on bridesmaid dresses and I usually wore long sleeves and the dress was sleeveless and she saw it, and I thought I was so pretty and she was so focused on that (with laughter). So, that's when she saw it and I'll never (pause) just seeing her reaction just like changed everything. She was hysterical. I've never seen her (pause) like, I've seen her cry, but never, never. I've never seen her like that. She said, "I am going to quit my job" and she was really heartbroken and I never wanted to put her through that. And I realized then that it was very selfish of me what I was doing and it didn't make sense anyway and I was hurting other people. So that was the last time.

Tara says she wasn't sure why she was cutting herself. "I couldn't tell you why, but I was really depressed." Although she regrets hurting her mother, she believes that cutting herself "served a purpose" because it made it easier to talk to her mother about what she was going through:

I didn't even know myself what I was going through. It didn't make sense to me. I had told her I thought I was depressed, but she kind of blew it off, so I didn't feel like bringing it up again. So it was kind of way for me to handle it I guess (with laughter). Umm...I wanted to talk to my mom. I just didn't think she would

understand. I was really wrong, and didn't know how to handle it. It (cutting) was really stupid. I just didn't know how to ask for help, so I did that.

She was not prescribed medication and only attended therapy three times. "I didn't want to talk to them, so my mother stopped making me go." However, she began to talk to her mother more about her feelings and depression.

Tara believes she did not "completely get over (her) depression, but overcame it in a way." She received a lot of support from her mother and a close friend. She fought a lot with her father when she was growing up and described herself as "an overly sensitive kid...everything upset me." Her father has also been diagnosed with depression, and Tara feels that may be one of the reasons they argued so much, "Well, I guess two depressed people don't get along very well, that is why I didn't get along with him. I still don't consider having a great relationship with him, but it has gotten better since he moved out."

When Tara was 17 she begin to have trouble sleeping; she did not want to discuss it with her mother because when she first told her mother she was depressed (when she was 14), her mother dismissed her concerns, "She was just like, 'no you don't' (have depression)." However, her symptoms became worse:

When I was lying in bed, I would just think of everything that could go wrong the next day, everything I could mess up or do wrong, as far as school, my boyfriend; I didn't even know what it could be. I just thought about everything, and everything that could possibly go wrong. My heart would race, then it would

happen during the day too sometimes, but I remember it mainly being at night. I would just think all night and my heart would just race.

A month after her 18<sup>th</sup> birthday, “as soon as I was legal,” Tara made an appointment with her doctor “and didn’t think twice about it. I’m glad I did it.” The doctor diagnosed Tara with mild depression and generalized anxiety disorder (GAD). She says she was not surprised by the GAD diagnosis:

I kind of expected it; I wrote all my symptoms down. I thought he would say GAD, but I didn’t know, like it’s funny, he actually has a poster on his wall with all the GAD symptoms, and I was like that I have (with laughter) so it wasn’t too surprising.

She also felt relief “to know I wouldn’t have to live with that anymore...it was nice to have a name to what I’ve been going through.”

She is currently taking 10 mg of Lexapro and finds that it helps, “It’s not perfect, I wasn’t expecting to be completely cured, but it is a lot better.” She also feels that it has helped her transition into college:

I did well in school, but I felt like I couldn’t concentrate as well as I wanted to. So taking medicine really helped me as far as getting the sleep I needed and being able to concentrate on the work I needed to do. So as far as transitioning to college it helped a lot...because of the anxiety of moving to a city and living on my own.

Tara did not tell her mother that she was taking medication for GAD until they went to the doctor for other reasons. When she found out “She (her mother) was upset that I

didn't tell her before but she understood why. I could have told her and I wasn't hiding it from her. I just didn't want to bring it up, but she's more understanding of it now."

After graduation, Tara plans on attending a doctoral program for audiology. "That's the plan," she said laughingly. She originally was a pre-med major but when she took chemistry:

It was very hard for me and I didn't want to bring my GPA down, and I didn't want to spend two years of my life taking chemistry classes and it stressed me out more, because I get stressed out easily, and it would frustrate me. I knew I wanted to help people in some way. Audiology was a way that I could take anatomy classes and be a doctor (with laughter). It sounds like the easy way out, but...yeah...it was the right decision.

She considered majoring in psychology, but didn't want to "make it a career because it was very depressing, but I knew I wanted to help people." Tara is also involved in a mental advocacy group called Active Minds, "It is a club on campus. Their goal is to erase the stigma and provide mental health advocacy and we are trying to set up a peer mentoring sort of thing, so if people have problems, they can come talk to us."

Although the medication is helping her, she still has difficulty sleeping and not "getting too stressed out." However, she has found ways to manage her anxiety, such as listening to music, watching TV and giving herself breaks. She also maintains a positive attitude, "No matter how bad it may seem...there is going to be a way for you to overcome it and still be successful. That is the main thing."

### *Analysis of Tara's Experience*

Tara, the youngest participant in the study and the most recently diagnosed, has quickly accepted her diagnosis and recognizes its impact on her life. Several themes are evident throughout Tara's description of her transition experience: 1) Challenges Related to Anxiety; 2) The Impact of GAD on her Relationships; 3) The Positive Impact of Diagnosis and Treatment; and 4) Developing Coping Strategies and Seeking Support.

*Theme One. Challenges Related to Anxiety.* Before Tara began taking medication, her feelings of anxiety mainly affected her ability to sleep and concentrate. She had trouble sleeping because that is when she has "time" to worry:

When I keep busy I didn't have a lot of anxiety problems, but whenever I just didn't have anything to do, lying in bed, I would just think of everything that could go wrong the next day. My heart would race, then it would happen during the day too sometimes, but I remember it mainly being at night. I would just think all night and my heart would just race.

The medication has lessened her feelings of anxiety, but "it isn't perfect."

She also found it difficult to concentrate, "I couldn't get into reading stuff, and I forced myself to do it but it was very hard, and I always procrastinated, always. But I had to do intervals when I would read and it was very hard to concentrate." Again, her treatment has helped but she still "gets anxious at times." Although "things are a lot better now," she still struggles with insomnia and being able to relax. "Sleep is still a huge issue for me. It's a challenge to fall asleep at night and stay asleep. It's a challenge not to get too stressed out." Tara feels that her GAD does create more challenges for her:

I don't think people get as stressed out as I do about little things. I am very sensitive so little things will make me sad. I don't think many people have to deal with that. Umm... (There are also) pressures as far as school. I think I have to work as hard as anyone else, maybe a little bit more because of the concentration aspect.

*Theme Two. Impact of EBD on Relationships.* Tara's anxiety has had a dichotomous impact on her relationship with friends and family. At times, she finds it difficult to express her feelings, and she has been reluctant to share her diagnosis with others, which has created distance between her and her loved ones. However, she also finds comfort and support from her relationships, particularly her mother.

When Tara was dealing with depression as a teenager, she found discussing her feelings difficult and started cutting instead. "I couldn't really talk about it...when my mom found about it (the cutting), it opened the lines of communication." Only a few people knew about her depression, including her boyfriend and parents, but felt they had trouble understanding what she was experiencing:

My dad has depression, so I guess he kind of understands. I didn't talk too much about it when him so I don't really know what he thought. For my mom, it was really hard because she's the kind of person that is very strong, and can deal with a lot.

Tara did not confide in her mother regarding her feelings of anxiety; in fact, her mother did not find out Tara was taking medication until they went to the doctor for another reason:

I am really close with my mom but it is hard for her to understand because she is a really strong person herself and didn't understand why I couldn't deal with the things she could. So I actually went to the doctor by myself...I didn't really tell her until we went to the doctor because I was sick and she asked for the medications and my mom was like, "What? Aaaaah!" (with laughter). So I told her and she was upset that I didn't tell her before but she understood why. I could have told her and I wasn't hiding it from her. I just didn't want to bring it up. Currently, her father does not know Tara has been diagnosed with GAD and is taking medication. Also, only a few of her friends know about her EBD:

I didn't tell anyone, really. I told my boyfriend after I've known him for a long time. I told a couple of my friends I had GAD because they saw me take my meds and asked what it was for and I couldn't think of an excuse (with laughter). So I just asked them not to tell anyone else.

When her friends did find out, she says "It didn't affect my friendships at all. Umm (pause) they took it for who I am." She has not disclosed either her depression or GAD with her best friend, which she is ambivalent about:

One of my best friends, I don't think she would understand. It's just not something I want to bring up. Like if she asked me, I am sure I would talk about it, but I just don't like bringing it up... I feel like if she did ask me we would have a conversation and I know that she would understand. I kind of contradicted myself, but I think I could have talk to her. And there is distance between us, but not significant distance.

Although Tara has found it challenging to talk about her feelings of depression and anxiety, she believes her mother and her friends have been a source of strength for her:

My mom, I mean she's like a rock, a shoulder to lean on; I can talk to her about anything. It was hard for her to understand at first, but when she figured out that I had problem, she was very supportive and didn't push me any less though...she wanted me to go school and made sure nothing got in my way.

Specifically, when she was struggling with Chemistry, she turned to her mother for advice:

I just found out I failed a Chemistry test and was thinking about dropping out. I never had trouble in high school. I had studied two weeks for this test and I took the test and I felt good about it and thought I had done well and I ended up getting up 55% and I was devastated because I had never failed a test before. It was a shock for me. The next day I was hysterical crying. I hadn't really cried since that day since I'd been here. And I was crying hysterically on the phone. And my mom said "It's not for you...you are not enjoying it. Everyone has something they are not good at. You are not going to be good at everything. You are still going to be successful. I am not any less proud of you." And just hearing that...I already think I knew it, but just hearing her saying just made everything a lot easier to deal with.

Her boyfriend has also been very supportive:



He actually takes meds for ADD, so he could kind of relate. So he knows that sometimes people have to take meds. He didn't know me when I went through my depressed state, but I told him about that, and he understands because he went through certain similar times in his life...when I told him about the GAD, he gave me a hug and said he understood. That was his first words and I felt like a weight was off my shoulder, someone understands me. It was a load off.

Tara admits that she has trouble "opening up" to people and trusting them, but believes that the reactions of those she has disclosed to have helped her, "Their reactions have been understanding and helpful, so it has helped me become a better person too...more accepting of myself and of other people." She identifies her friends and mother as her only form of assistance besides medication. "I talk with my friends and mom, of course, that is pretty much it. I just want them to listen. That's all I ever ask for."

*Theme Three. Positive Impact of Diagnosis and Treatment.* Tara was not surprised by her diagnosis of generalized anxiety disorder; in fact, she "kind of expected it." The diagnosis has helped her understand herself more:

I think it kind of made me get to know myself a little bit better, because I understand none of it is my fault, it is a biological thing. And I know I can improve myself and get better at it. It is a benefit knowing that's what I have. It helps to have a diagnosis.

She does not feel that it changes who she is or the way she sees herself, "I just see it as who I am. I accept the fact that's who I am, and just kind of try to move on from that."

She also believes the medication has been helpful, "It's so nice to sleep." Tara has

positive feelings regarding both her diagnosis and treatment, “It was nice to have a name to what I’ve been going through. It was a relief when they said we are going to give you some medicine to try, and it was such a relief to know that there is...things aren’t perfect, but they are a lot better.” For example, Tara used to have trouble sleeping several times a week, but since she has started medication (six months ago), “it has only happened five or six times.”

*Theme Four. Developing Coping Strategies and Seeking Support.* Although Tara has found medication beneficial, she still sometimes struggles with sleeping and concentrating, and is still developing coping strategies and becoming comfortable with seeking support. Tara has utilized several techniques to help her when she has trouble sleeping:

(With a sigh) I just try to fall asleep anyway that I can. Brush my teeth, go to the bathroom. Just sit up in bed for a few minutes. It is very hard when I wake up in the middle of the night to go to sleep. Umm (pause) I’ll just like walk around and hope my roommates don’t see me walking around and think I am crazy (with laughter) or I’ll watch TV...it’s trial and error.

She also experiments with ways to lessen the pressure she feels regarding school:

I give myself breaks. Like when I am trying to read a book and I am really having trouble concentrating, I’ll get some chocolate or watch 10 minutes of TV, or go on the computer and then go back and read a certain amount of pages. What I am trying to do now which I’ve never done before is trying to get the work done before it is due, and not the night before (with laughter), so that is helping too.

She also believes that her drive and determination have helped her succeed:

I said failure is not an option for me so I'll do whatever I have to do to make sure I do the best I can, regardless of any mental issues I might have. I'll do whatever I can to make sure nothing gets in my way. I hate failure; I hate it. I can't fail at something or I will be devastated so I'll do what ever I can to not fail.

She has also discovered that ignoring her problems increased her anxiety, "Now, if there is a problem, I try to address it, before I started the meds, I would get anxious for no reason."

As previously discussed, Tara is able to seek support and find comfort from her mother and some close friends. However, she still has difficulty asking for help, "It is difficult to start talking about it, and it is difficult to say in words what you are feeling and you do not even know." She also identifies her seeking treatment for anxiety by herself "as a victory" because she was "so nervous; I wrote everything down because I was afraid I would forget. I was shaking the whole time." Tara is uncomfortable asking for accommodations or seeking assistance from professors:

I don't give myself excuses (pause) for me personally. For other people it would be okay. But for me I don't look at that. I kind of look at that as pity (pause) I guess the way I look at it if I had to ask it wouldn't be because my disability is holding me back. I see it as I am using it as an excuse.

### *Impressions*

The most salient aspect of Tara's experience is the recency of her diagnosis. She is the youngest participant in the study and was diagnosed eight months prior to the

interview, and she appears to be in the process of understanding how her EBD affects her and her sense of self.

*Recency of Diagnosis.* Tara has been recently diagnosed with anxiety disorder and the “newness” of this diagnosis is evident in her narrative. Her responses were often repetitive and less in-depth than other participants, and hers was the shortest of the participants’ interviews. When probed or asked to clarify an answer, she would often repeat what she had previously said, or say “that’s it,” or “there’s nothing else to say.”

A repeated theme throughout the interview was how the medication has benefitted her, particularly during her transition to college, but that she still experiences anxiety and stress. “So as far as transitioning to college it helped a lot. I haven’t really experienced anything bad. I was stressed out, which is normal. But it probably would have been a lot more.” Several times she mentioned how things are better, but not “perfect” or that she still “gets stressed out.” “But now it’s not as bad any more. But I do get too stressed, but then I just give myself a little break once in a while.”

*Sense of Self.* Because Tara is still in the process of dealing with her EBD and developing her identity, her responses sometimes seemed inconsistent or incongruent. She has developed coping strategies, which have “helped a lot, especially talking to my friends,” and is active in an outreach group for students with emotional or behavioral difficulties. She also sought treatment on her own shortly after she turned 18. However, she admittedly has trouble expressing her anxieties and feelings, “It is difficult to talk about it when you don’t even know what you are feeling.” Also, most of the people who know that she has GAD found out accidentally (e.g., her mother and her roommates).

She is also reluctant to seek other forms of assistance that would require disclosure, such as therapy or accommodations from the Office of Student Disability Services. Furthermore, she was often self-critical, saying things such as “I am just a sensitive person and am hard to deal with at times” or “I don’t handle things well.” However, she is also aware of, and proud of, her achievements, such as seeking assistance on her own and attending college. She also sees herself as needing friends and “a lot of support” but also describes herself as “independent” and “determined not to fail.”

Throughout the interview, Tara demonstrated a desire to help other people, as illustrated by her choice in careers and membership in an advocacy group. When asked if there was anything else she would like to add to the interview, she offered this advice for others who are struggling with a problem:

No matter how bad it may seem, even if it seems like it couldn’t get any worse, there will always be someone who can understand. There is going to be a way for you to overcome it and still be successful. That is the main thing.

*Kristi*

Kristi, an engaging and affable 22- year old Caucasian female, is a recent graduate of a large urban university. At the time of the interview, she was finishing her Bachelor’s degree in Special Education. She graduated several weeks later and has been hired to teach students with Autism at a local elementary school. Her responses were peppered with self-deprecating humor, nervous laughter and sometimes tears. In fact, she became emotional a few times during the interview, particularly when she talked about

her challenges. She talked rapidly and switched tenses frequently, particularly when she was relating conversations with other people. She often apologized for “talking so much and rambling.” Her answers often seemed to spill out of her, as if she felt an urgency to share her story.

Kristi was diagnosed with “severe depression and anxiety” when she was 18 years old, during her first year of college. She was later diagnosed with generalized anxiety disorder (GAD) by another psychiatrist. However, she started experiencing “anxiety issues” when she was in high school:

My mom has bipolar disorder and she is unpredictable and a lot of times very angry, and I didn’t really know how to deal with her and I was always having panic attacks and always worried. So I put everything into my schoolwork.

Her mother’s mental health difficulties permeated Kristi’s narrative:

At home, my life was crazy. At first, college was pretty easy. But I found myself being overly anxious all the time and I couldn’t sleep and I was very depressed, and I didn’t know how to deal with my mom and I couldn’t be close to my friends. The more I guess, the more difficult my relationship with my mom became, the worse I felt...and my mom tried to commit suicide several times (with a sigh). One time, she overdosed on her meds, Xanax, and I was there. She came into my room and like was yelling and screaming at me, and cutting herself. It was really intense stuff. I called 911 and they take her and I was just left there and pretty much said, “What the hell is this (with laughter)?” I was pretty much overwhelmed...after that, I didn’t care about anything.

Because of her mother's own EBD, Kristi felt a lot of pressure and responsibility at home. "My dad always was working. My mom couldn't work, or keep a job. Every other day it seem liked she was in and out of working (with laughter). (I have a) younger brother; I took care of him most of the time." After she started college, "it seemed like life became for stressful, and it was harder to cope." She began to have anxiety attacks frequently. "I was working with children in an after school program and I would have to leave and have somebody watch my class so I could step outside. I figured I should go talk to somebody because it wasn't normal." Her mother was resistant to the idea of Kristi seeing a therapist:

I went to my mom at first and told her I thought I had the same thing she did (laughs). She says "no, no, no you are not like me at all." "But mom, you don't understand I have these panic attacks, I can't breathe, I am constantly worried; I don't eat like I should, or sleep. I need to go to the doctor," and she said, "You're not crazy, you don't need to go" Finally I made my own appointment and went.

Kristi first went to a therapist and requested medication:

I wanted meds right away; I wanted a quick fix (laughs) and take meds. I don't want to talk to anyway (laughs). But no, you have to go to a therapist first... she wasn't ...ummm...the right person for me. She would give me homework and things to read and stuff to do. I felt like I couldn't even get things in my life done, how am I going to do this stuff for this woman? I was telling her I would come back, but I don't feel better, the techniques aren't working for me. She says "I can't help you anymore."

About four months later, she saw a psychiatrist and was diagnosed with “severe depression and anxiety,” and placed on medication, but Kristi did not respond to it well:

She started putting me on I can’t remember...a medication...Remeron<sup>19</sup>...that’s what she put me on first. It made me a zombie, didn’t want to get out of bed, didn’t want to work, didn’t want to do anything but eat or sleep. Sometimes I would wake up and feel like I couldn’t move. So I stopped taking it because it wasn’t working...I was then put on Paxil and it worked great for a while...I completed my work, and got into the College of Education.

After a while, the Paxil “stopped working.” She went to another doctor and was diagnosed with GAD, but after a few unsuccessful experiences with medication and therapists she “decided not to take medication for a while.” She admits that she needs to return to therapy:

I’m okay but I have moments, where it’s...especially right now. It’s been really hard. I get so overwhelmed and I know I have anxiety attacks and I try to stop them before they come but I can’t focus, I am all over the place, and it is hard...getting quality stuff...it is hard. Even when you read my writing, it is just all over the place. Generally, I pride myself in my writing and abilities, and I just can’t do it.

She would like to go back to a therapist “but it’s expensive and until I find a job that has insurance, I can’t.”

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<sup>19</sup> Remeron is a psychotropic medication used to treat depression. Its generic equivalent is mirtazapine.



After she teaches “for awhile,” Kristi plans on attending graduate school and earning a Masters in Communication Sciences. She wants to be a communication therapist for children with autism, and “eventually run my own after school center for children with autism...it is a very long term goal...one step at a time (with laughter).”

### *Analysis of Kristi’s Experience*

Although Kristi was close to reaching her academic goals at the time of the interview and has since successfully completed college, her emotional and behavioral difficulty has complicated her transition experience. She continues to struggle with anxiety and panic attacks, and at times, has trouble completing personal and academic tasks. Her narrative reveals five central themes that have affected her transition from adolescence to adulthood: 1) Impact of EBD on Self-Concept; 2) Academic Challenges Related to EBD; 3) Issues Related to Treatment and Assistance; 4) Impact of EBD on Relationships; and, 5) Coping Strategies and Support System.

*Theme One. Impact of EBD on Self-Concept.* Kristi is ambivalent towards her EBD; in some ways, she is “relieved” by the diagnosis, but she finds the symptoms of anxiety challenging and difficult to deal with:

I knew I had something wrong with me, because none of my friends would react the way I would to things. And I knew it wasn’t normal to have panic attacks and to feel scared (with laughter). So, when they told me I was like, “Yeah, okay... so I was a little relieved actually to find that I was right.” Because before I thought there was something wrong but (I thought) maybe I am just overreacting you know, maybe it is a phase and it just seems to get worse, the more I let it go and

um...so the diagnosis itself at first it was an eye opener and now it's just something I have to deal with (with laughter).

She finds living with GAD:

Kind of bothersome, the label isn't so much (a problem), but it is the fact that I have to struggle is (pause). It's hard, it's very hard. Because I want to be able to wake up and have energy and do the things I want to do and be excited about my work and getting things done with school and all I can think about is 'Omigosh.' And even when I think I make progress, I think there has always something to worry about. Always.

Throughout the interview, Kristi was critical of herself and her inability to cope with her depression and anxiety:

I had a friend going through similar things and he was going to his therapist and it was working out for him. So I thought, "Wow, there is something really wrong with me. All he had to do was go to therapy."

She also feels that she does not handle stressful situations as well as other people:

I guess you could say because where everybody else has everything organized and so with it, I feel like I am over the place. I'm sure they have struggles too. But I constantly feel like if I only could be that person that gets everything done in advance, then I wouldn't have to stress out and worry and have this anxiety. But I get anxiety issues dealing with that, just to organize things. You can look at my apartment, it is a mess. It's so (pause) I have clean clothes on the floor and dirty

clothes on the floor (with laughter). Even putting things away now has been an issue.

Her anxiety and stress were evident during this statement, as she raised her voice for emphasis and used multiple hand gestures. She also feels that she is to blame for her anxieties and feelings of pressure, and sometimes has trouble remembering that her challenges are related to her EBD:

I feel the need to get things done and to be the person that everybody thinks I am. I think I make those things (challenges) for myself, which is even harder because when I say I have to do this, they say “no, you don’t” and I try to blame it on them, but really it is me, and not them. And that’s difficult to deal with. It’s harder for me to deal with the fact that I am doing this to myself. It would be so much easier to say “it’s their fault.” But it’s me, how do you fix yourself?

She often feels different and dissatisfied with herself:

I want to have the normal (experience), to be able to get assignments and complete them in a timely fashion; I don’t want to have to take forever to do things. I want to be dependable and reliable. And a lot of times I beat myself up for it because it is not how I work. And it is hard because I want to be able to do things the way everyone else does. I want to do things in advance and have time to rest, but it never works out for me.

Kristi’s diagnosis has also changed the way she sees herself, “I feel like I’ve become a special needs person...and sometimes *I lose who I am.*” She is also hesitant to share that she has an EBD because of what people might think:

I don't like to openly say I have a disorder because I don't want them to feel sorry for me, and I don't want to feel like I am blaming everything on that. It is a small part of who I am. So, it is something I am battling with, and would love to have under control, but I don't want it to consume me or for it to become a crutch for me.

*Theme Two. Academic Challenges Related to EBD.* Kristi found high school and the first year of college “pretty easy...I didn't have to study or do those things...but then I found myself being overly anxious all the time and I couldn't sleep and I was very depressed.” Kristi now has difficulty completing assignments because of her desire to be perfect, which then increases her anxiety:

And it (perfectionism) is what usually keeps me from completing things a lot of times because I want to be absolutely perfect and if it's not, I don't want to give that to something. I'll write papers sometimes and I'll worry and worry and worry that the paper is not going to be good and I won't get the grade I need. And once something gets done and turned in, it (the anxiety) should be finished (with laughter). But it continues on and on until I get my grade or I get the opportunity to review it.

Her increased anxiety also causes her to procrastinate because she has a hard time concentrating and focusing:

I have moments, where it's (long pause) especially right now. It's been really hard, because everything's so...just pressure on me. I would just put things off. Hopefully, I'll be graduating this fall, but my ESOL binder's due and I have

things like that due and I have a very hard time focusing. I get so overwhelmed and I know I have anxiety attacks and I try to stop them before they come but I can't focus, I am all over the place, and it is hard...getting quality stuff...it is hard. Even when you read my writing, it is just all over the place. Generally, I pride myself in my writing and abilities, and I just can't do it.

She has also dropped classes because she was unable to complete the work; "I'm taking a class for the fourth time this spring...during my internship. I'm determined it's my last one (with laughter.)"

Feelings of anxiety have also affected her ability to stay motivated:

Motivation is my number one issue. I have nothing in my ESOL binder, absolutely nothing. In fact, I've kept everything because I know I have to keep and I have boxes, but when I look at it (with laughter) I feel sick, like overwhelmed and I talk to other people about it and they are all done and I even have somebody to look at it and I know I have what I need but it is just doing it. I can't do it. I can't bring myself to go through it is so overwhelming to me because I am so unorganized. And it is the whole thing of, what happens if I don't have what I need? What happens if they tell me I don't have my stuff? And I don't graduate, or have to delay my graduation again. So it's like if I avoid it all together (with laughter)...I won't have to deal with it, which isn't the case. But I convince myself of that some days (with laughter)...I just want to get to a point where I'm not like that. Where it's not so difficult, and it's me, and that's really hard to deal with too.

As she said the last statement, that “it’s me,” Kristi became slightly teary and paused for a minute or two. Again, she has difficulty understanding, or accepting, that some of her academic and personal difficulties are related to her EBD. “I make those things (problems) for myself, which is even harder because when I say I have to do this, people say ‘no you don’t’ and I try to blame them, but it is really me.”

*Theme Three. Issues Related to Treatment and Assistance.* Kristi has sought help from several therapists, doctors and psychiatrists, and has mostly been dissatisfied with the results, although “some of it was helpful.” She initially just wanted to take medication and was resistant to therapy, but went anyway. Her first therapist “wasn’t the right person for me,” and referred Kristi to a psychiatrist who put her on Remeron, which made her “a zombie, (I) didn’t want to get out of bed, didn’t want to work, didn’t want to do anything but eat or sleep.” She describes her relationship with this doctor as:

Awkward. She blamed it all on my mother. She wanted joint sessions with my mother. And then my mom started seeing her coincidentally; we didn’t know we were seeing the same doctor. That’s when it became weird because we would talk about my mother and then my mom would come in and talk about me. It was tough because of the boundary issues.

However, she stayed with the same doctor because she:

Couldn’t deal with change. She did put me on Paxil and it was great for about a year and a half or two years, but then I started feeling really depressed and upset again...it became harder and harder to cope again. I quit my job, all my jobs.

During this time, she also experienced a lot of changes; she moved into an apartment with a friend, and started attending school full-time. When she entered the special education program, she found “the workload was a lot and it was a constant battle to get it done because I would get so overwhelmed with everything.” She also felt additional pressures from her relationships:

I had a relationship with a boy which was negative. I couldn't deal with him being negative and school being overwhelming and not having a job, and dealing with my mother, and became very depressed. I started self-mutilating, which I had done previously, like at 16, during crazy times. I was cutting my arms, and I had suicidal thoughts and I couldn't deal with things any more. I just wanted everything to stop. Just freeze for a minute and let me, I felt like I was suffocating.

She decided that the Paxil was not helping and she “had to get off of it:”

I told the doc I couldn't do Paxil anymore, not having positive effects. She ummm, she told me “Well, we have to slowly take you off it.” Well, I had stopped taking it all together (with laughter), and I hadn't taken it for a couple of months and you have severe withdrawals from it. And I guess there is a reason you slowly go off of it. I was jittery, worse than I normally, and it was bad, so I decided I didn't want to do meds anymore. I refused to do it. So I went another year without it and it was hard, very hard, and there were times where I just thought I can't do this anymore.

Kristi decided to go to another psychiatrist who diagnosed her with GAD and prescribed her Xanax. She was reluctant to take it because of her mother's experience:

I freaked out because that is what my mom overdosed on, and I told him that, but my mom was going to him too (with laughter). But at least I knew this time and he was doing great things for her. She had been finally stabilized and living a pretty normal life, so I figured if it works for, it would work for me. So that is what he prescribed me, and I was like, are you kidding me? I can't take this. And he was just like, well try it and see if it works for you, and I was like "*NO, I can't take this.*" I had it filled and took for one night, or one month rather, and I noticed they were missing...my mom was taking them. I went back to him and told him I couldn't do it. He prescribed me something else and I decided I wasn't going to take meds.

During this time, she was also seeing a therapist, but was again dissatisfied:

I went to a therapist too, and he was like "you are doing great; you seem to have everything focused." It is so easy to tell them everything is fine. Seemingly I was okay. I had an apartment, friends, doing well in school, goals. So unless I actually told him what was going on (with laughter)...but I didn't, my mom was seeing him too. It's hard for me (pause) with the other doctor, it was a parallel. Everything came back to her. It was always about my mother, it wasn't about me. And I was the one having problems too.



After this experience, she “had enough,” and hasn’t “done any medication, therapy, or seen doctors for about a year and half now.” Kristi felt there was one benefit to seeking assistance:

Being able to actually go was probably more help than being there. Coming to terms with the fact that I needed to be helped was much more of a leap, much more progress than actually going...I’ve had very little success (with counseling and medication) unfortunately.

Kristi is still open to the idea of counseling, and is planning to seek treatment once she has full-time job and insurance:

When I first went I felt bombarded with all this stuff and it was too much. I didn’t know how to deal with anything. And having time to be away from all of that and to reflect on who I am and what I am doing and my struggles, and analyze myself, I was able to deal with the issues at hand, not necessarily did I deal with them positively, but I was much more able to accept myself. And now that I’ve gotten to that point, when I go back into counseling, it is going to be from a different perspective, a different purpose, it is not going to be “fix me,” it is going to be “I know what’s wrong, help me cope with those things,” it is a more specific thing, rather than “I don’t know how to deal with anything” so I think it will be much more positive.

Kristi also tried to seek assistance from the university’s counseling service:

One of my professors referred me to the counseling center a couple of times, but it’s a waiting issue. It’s like any other psychiatry. You make an appointment and a

couple months later and once the appointment comes I'm like "I feel okay, I don't need to go" (with laughter). I know I do this to myself; I've dealt with this enough to know I do this. But it's still hard to make myself go.

Overall, she found the experience frustrating and time consuming:

I think that making the process to get supports a little less stressful would be beneficial because going to the tiny office with the big sign that says "student disability services" is a little intimidating. And I actually made it in there, and then I found I didn't have the paperwork needed. And I felt just to make it through those doors was hard enough. I'm not coming back. So if you could do it through somebody, like a professor, or somebody you trusted. Even if you had to turn in the paperwork into them would be a whole lot easier than being isolated. I mean I understand the reasons behind it, it's just there are so many people I know have the same issues I do and don't want to go. It is intimidating and tedious, and when you are stressed out about everything, it is one more thing.

She has found talking to her professors and asking them for additional time and support to be the "most helpful; I've had some pretty understanding professors who would work with me. Sometimes they are hard to get a hold of, but overall, they have been great."

Overall, however, she has found the process of seeking assistance difficult and futile, "So it's just hard. And I don't know what my options are... If I get disability services, so what? What does that mean? I don't know what that would do for me." However, she sometimes thinks:

That I would be better off if I would have disability services, and got all of those things worked out because now I'm in a situation where I am about to graduate and the pressure is just so much. I've already pushed my graduation back a semester just because I couldn't do it all. And I don't want to have to keep doing that (with a laugh). That's not fair.

*Theme Four. Impact of EBD on Relationships.* Kristi often hesitates to disclose her EBD to friends because she is concerned about how they react, "I worry they are going to think, one, I am trying to have somebody pity me. Two, that I'm being dramatic because I'm always worried about that, or three, thinking that I'm going to be needy." However, she has experienced mostly positive reactions from her friends and family:

Most of the time with the people I shared with that I really know me, they're like "I'm glad you've finally come to terms with it. We've all known that Kristi gets stressed out because of this, or Kristi is this way." But I had a really hard time dealing with it. So when I shared it with some of my closer friends, they were happy for me that I had finally done something about it.

Kristi does feel like people dismiss her thoughts and feelings because she is "dramatic:"

For the majority of my life, a lot of people just said I'm being dramatic. If I hear I'm being dramatic (pause) *I swear*; it gets under my skin. And obviously I don't react to it but umm, I feel, I dunno, I feel like I'm awkward. They tell me I'm dramatic and overreacting, and then I get self-conscience and tell myself, "maybe I am overreacting, but I can't help it (with laughter)," but I've had some people that are very accepting. Like my boyfriend is very accepting and very supportive,

and I've had some friends that I've known prior to being diagnosed. That were like, "yeah, we knew all along."

Kristi also has difficulty trusting others. "I don't want to be vulnerable. Because I've tried in the past to have people care about me and be there for me and be excited when I do things, and it never usually pans out." When she is hurt or feels "betrayed," she usually "internalizes" her feelings:

I don't like to confront people. I would rather deal with it on my own then have to worry about what would happen. It's that whole anxiety thing; like so, I tell them, and then what? I don't want to risk that. I don't want to put myself out there to get hurt more.

Kristi's relationship with her mother is one of her most significant and challenging relationships, and has impacted her life in many ways:

At home, my life was crazy. My mom has bipolar disorder and she is unpredictable and a lot of times very angry, and I didn't really know how to deal with her and I was always having panic attacks and always worried. So I put everything into my schoolwork.

Her mother influenced her friendships and the way she saw herself, "I didn't know how to deal with my mom and I couldn't be close to my friends." When she decided to seek assistance, her mother was resistant to the idea, "She said, 'no, no, no, you are not like me at all.'" When Kristy finally did see a therapist, she again felt her mother's presence "suffocating" her:

And once my mother got involved, it was no longer beneficial because they want to do joint counseling sessions, and I didn't want it to be about her, and I still don't want it to be about her. Because my issues with her have nothing to do with my disability; I'm sure to a certain extent, it's not about her, and it always seems to come back to that. And even when I talk, I find myself talking about her all the time (with a sigh).

Her mother and father moved to another state recently so their relationship is a "bit better." Also, her mom now accepts Kristi's EBD, which makes Kristi feel uncomfortable:

My mom has (pause) she's jumped on the bandwagon. "You're crazy like me, you're just like me." We have this in common kind of thing. And that's you know (pause) I don't know. That affects me. I try to think as myself as not being to the extreme she is because I know she is my life was when I was living with her and I love her, and I don't have (pause) it's just, I don't want to be that person. I don't want to hurt people the way she did. I don't want to be lumped in with her, because again I am my own person.

In fact, Kristi is determined to "be her own" person and not let her mother "control" her or her life:

I'm so tired of dealing with my mother; I've moved on, my mom and I have a pretty decent relationship now, it was a period in my life that a lot of crazy, unstable things took place but I've moved on so I don't want everything I do be about her. Because I have this issue, and its part of me, it has nothing to do with

her, other than the fact that she contributed to it somehow, so I would rather focus on the more specific things that I can do to help myself.

Kristi's intimate relationships have also been affected by her EBD. She is currently in a "loving, supportive" relationship, but recognizes that her anxiety and stress "are a constant battle:"

I'm living with my boyfriend; we've been together for almost two years. He's very supportive, one of the first people in my life to be supportive and understanding. But some days I don't even want him around, which is normal to a certain extent, but other times, I'm like, I'm just going to run and leave. I get so anxious and panicky. (It's a) constant battle, I think I want to run away.

Obviously, I know my problems are going to follow me. I'm not insane.

Prior to her current relationships, Kristi says she usually chose:

The wrong guys and got into destructive relationships (with a sigh). Dating was crazy. It was me constantly to find somebody to get me and love me. Even though I have, you know, issues. And I kept finding people that had more serious issues than I did, and I wanted to help them, and be there for them. But I needed somebody to be there for me. And it was always these one way relationships. I had one boyfriend who would yell at me and told me I was crazy, and he was cheating on me. I still loved him; I thought he was the best thing in the world. And he would yell and scream and threaten to hit me, and I was afraid of him toward the end. And my other (intimate) relationships were like that too. I would always find these people that had family issues or things like that because I could

relate, and I expected them to be open and supportive like me and they weren't. And I had a really hard time dealing with letting go. I wouldn't get over relationships. And then it became a physical; I would just have physical relationships. And after, you know, several years, from the time I was 15 until I was 20, I was back and forth. I would either have a relationship that was negative or I would have a relationship that was nothing, that was just a strictly physical thing and I would move on. And I would feel what is it about me that nobody wants to love and be with me? I was always being left, I would never leave; I would stick it out, no matter how bad I was treated. But then I met Mark, and he has family issues too, but he was very supportive and was exactly what I needed. And he's still very supportive. And there are days when he needs me too and that's fine. It's nice to finally have somebody that just doesn't need physical things and isn't just out for themselves and really care about me. I've come to terms with who I am and what my needs are, and I can make myself happy; I don't need him. I just want his support, and it's much healthier than any other relationship I've ever had.

Kristi became teary and emotional during the above narrative, but wished to continue the interview. Kristy believes she was ready to be in a "healthy relationship" because her expectations changed:

My expectations were a lot different, before (she met Mark) I needed somebody to fill that void in my life. It's good to be in a healthy relationship. For a change, I don't have to worry about my love life. It's not something I stress about all the

time and it's nice. It's the one, calm, normal thing; it's consistent. It's actually kind of refreshing (with laughter).

Kristi finds it difficult to maintain friendships because she is:

A very unreliable friend. Sometimes, more so when things in my life are stressful. I have a tendency to make all these plans and I want to see my friends and do all these things, and it comes to the day we are going to hang out and I'm like, "I can't do it today." And they'll call and call and I'll ignore and ignore their calls. And they get frustrated, very frustrated with me. And I apologize and things like that, and then I feel bad because I feel like I am being a bad friend. I am always the first person there when they really need something; I can muster and be there for them. I am always listening and supportive, but when it comes to having fun and doing things. If I'm not distracted I guess I will just not go. They'll say, "We went out and thought you were coming" and I feel I'm more aware of it now. I'm the kind of friend that I didn't want to be and didn't like to have. And that's you know (pause) hard to deal with sometimes.

In fact, she regrets not disclosing her EBD to some friends because she "lost some friendships because I'm that undependable friend and I think that maybe they would have understood more, if I would have shared that sometimes things just become way too much for me."

*Theme Five. Coping Strategies and Support System.* Because Kristi is not receiving formal assistance currently, she relies on coping and self-management strategies:



It's a whole lot just trying to relax, and calm down, and take one thing at a time; I try to take things slower and I email my professor and I tell her "this is how it is," and I have other things going on and I'll get it when I get it...I can't just let it go, so I have to take a day or a couple of days and I sit down and devote entirely to school, and what gets done get's done and what doesn't get done I deal with that later on.

She does ask for assistance from her professors when she is feeling overwhelmed:

I'm usually pretty open with my professors "This is what is going on, this why I'm not getting it finished," they are usually pretty understanding. But I want to put my full effort into something and do it right; I don't want to halfway do something just because it is due, and I express that to them and usually they understand and a lot of them appreciate me being honest.

Kristi also tries to manage her anxiety by remaining focused on her goals:

I have this strong passion to accomplish things. So when I'm getting to the point when I just don't want to go on and I want to run away, I have to remember that I have to, it's expected that I graduate from college. But, I do it because I want, I eventually want to get to the point of my life where I am in control and I don't need to depend on somebody else. And I am doing things I enjoy and I am passionate about and I can't work with children with Autism unless I go to school and I can't do the things I want and buy the things I want and live the life I want unless I get through, so no matter how hard it is I know that I have to get through

it. And feeling sorry for myself isn't going to be the way to do it. It is not going to get me there; it is just going to make me regress.

Finally, Kristi is learning how to rely on a support system. "A lot of my family and friends, they're supportive and try to tell me 'It's okay, it's not, it doesn't have to be that way. You don't have to have everything done and things like that; don't beat yourself up' ...they think I am too hard on myself." In the past, she has had difficulty trusting people or maintaining friendships but has found "A really good group of friends, and of course my boyfriend that I can rely on."

### *Impressions*

Some underlying structures that permeate Kristi's transition experience include the way she perceives herself and the interaction between herself and others. Kristi is still learning to establish her own identity and define boundaries in her relationships. Despite many challenges due to her EBD and negative experiences with therapy and treatment, Kristi has met two significant goals, graduating from college and obtaining a teaching position.

*Self Perception.* Although Kristi recognizes that she has anxiety and depression, she tends to be self-critical and blame herself for her personal and academic challenges. During the interview, she repeated statements such as "I do it to myself," "I create a lot of pressures for myself," or "It's my fault." She feels that she makes everything an "issue," which increases her anxiety and decreases her ability to accomplish academic or personal tasks:

I can't sleep because I feel like I am weighed down by everything and I find outlets and I blame it in on things. So then my binder doesn't get done and I have piles of dirty clothes next to piles of clean clothes.

When asked if she felt that her EBD may create or intensify some of her stress or pressures, she allows that it might but wishes she were "normal" like everyone else.

*Interaction between Self and Others.* Kristi is still in the process of establishing her own identity, one that is not defined by others or their needs. Growing up, "everything was about" her mother and she feels that her mother and other members of her family still try to "lump them together." "People say 'Kristi is just like Ellen,' my mom says that too, 'you have what I have,' and I just want to scream, 'I'm not like you.' Because I don't want to be like her, selfish and irresponsible." She feels now that her mother has moved to another state, it may be easier to not be "so engulfed" by her mom. Kristi also finds difficulty establishing boundaries with her friends and students:

I don't want to always be in tune with other people's thoughts and feelings and worry so much about what they are thinking and feeling. I want to be ME. And sometimes *I lose who I am*. I really like art and music and things like that. And I don't ever pursue those things because this person needs this support, and I can be there and support them. And the child I work with that has Autism, they (his family) need me, so when I have spare time instead of doing things for me I am trying to help them because I always wanted somebody to be there to help me (sighing) that's who I am (with laughter).

Although Kristi has not found treatment that has helped her, and she still feels anxiety and has panic attacks, she has achieved her goal of graduating this spring. She finds motivation in knowing that, “Just because I have a disability doesn’t mean that I can’t still do those things. It’s just a little more difficult.” However, it is important to note that Kristi continues to battle depression and panic attacks. “It is a continuous struggle...it’s not like I’ve overcome it; I deal with it everyday.”

*Lisa*

Lisa, a soft-spoken 20-year old Caucasian female with wavy reddish-brown hair and hazel eyes, attends an independent honors college and is majoring in Philosophy. Her responses were thoughtful and measured. She often took several minutes to think about her answer and provided lengthy, detailed replies. Her background in philosophy was evident throughout her narrative, both in the way she perceived the questions and in her responses. Several times she questioned if her responses made sense, or if she answered the question adequately.

Lisa experienced a “really rough transition” from high school to college, which she attributes to the many changes she faced. She moved from South Carolina to Florida, and felt “a big culture shock” because “she was used to the way things were.” She was diagnosed with Generalized Anxiety Disorder (GAD) when she started college, at the age of 17, but felt depressed and anxious in high school:

I had anxiety all of my life but I didn’t know what it was; I didn’t know what was wrong with me. This was the first time I had ever been to any kind of mental health professional whatsoever. In South Carolina it is kind of a stigma, you have

to be really crazy to go to a therapist. So I didn't realize there was anything wrong with me or I could do anything about it."

Before she went to the counseling center at college, Lisa's anxiety increased:

My habits of not being able to ask for help, and ignoring as much as I could the problems until they overwhelmed me, and the way I dealt with my anxiety became too much. I was thinking that every month, two or three times I would have a breakdown, where I would cry and couldn't stop crying, and that was my emotional outlet, probably six hours long, but concentrated. It would come at the worst time, when I was so stressed out, about things that didn't matter, but I had no one to tell me they didn't matter, so I would have things breakdown. There was always a danger because I was so volatile that if I did open up that I would start crying, and I was afraid they would use it against me or dislike me, "that weak woman crying, what is she doing?" So it was ongoing, having those crazy emotional outbursts and (feeling) so emotional and dealing with the belief that I shouldn't be so emotional. I tried to train myself out of, having those emotions, which seems ridiculous now, because I couldn't control it.

She went to a therapist within a few months of starting college:

I was really confused, I thought college was going to be fun and exciting, but when I got here, my whole world had shifted and I didn't know what was up any more, and I was really, really depressed at that point, because I was scared, because I felt like I didn't know what was expected of me.

She was diagnosed with GAD because “it was so obvious” to the therapist and began taking Zoloft,<sup>20</sup> which was an “eye-opening” experience for her:

As soon as they started (I had) this turnaround and it was kind of a revelation to me. Because my parents have anxieties like I do; they have insomnia, but don’t do anything about it but just deal with it in strange ways and stoically stick it out, so I have that model. But when I got here it just broke down, keeping everything under control was impossible. But I hadn’t realized before I could do anything about it. I thought there was something wrong with me.

She was also diagnosed with depression because “when the anxieties were taken care of, I was just as depressed as before. That is interesting because you trust professionals to figure it out.” She is not sure which diagnosis is primary because the symptoms overlap. She is concerned about the possibility of becoming bipolar or schizophrenic, and is “counting down to when I am 26” because the age of onset for those disorders is typically before 25. She “got bounced around” on medication (with laughter) and is currently taking 1 mg of Klonopin<sup>21</sup> and 15 mg of Remeron daily. She says the medication is now working for her, “but it took a long time to get to this point, I was kind at the mercy of the western medical system (with laughter).”

She stopped taking medication for about a year and “was completely out of the system for awhile.” She felt that the medication wasn’t working and that treatment was all “bullshit.” She managed her anxiety and stress by using marijuana “throughout the

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<sup>20</sup> Zoloft is a SSRI that is used to treat depression and panic disorders. Its generic equivalent is sertraline.

<sup>21</sup> Klonopin is a psychotropic medication used to treat anxiety and panic disorders. Its generic equivalent is clonazepam.

day.” However, as soon as she came back to school, she went to the counseling center because she could not “live that way...it was a good experience in a way, now I know that meds and therapy help me more than I thought they did.”

Academics are very important to her family; both of her parents are scientists and have doctorate degrees, and her sister has been in college as long as Lisa has been alive. “She is 18 years older than me so when I was born she went off to college and she stayed there ever since. She’s just now becoming a real doctor because she hadn’t finished her residency (in psychiatry) yet.” Lisa plans to pursue a doctorate degree in Philosophy, but is also interested in earning a Masters in Social Work. She expects to attend college for “about 10 to 15 years,” and is undecided regarding her career goals. “I have no expectations (with laughter) about what I am going to be doing.”

#### *Analysis of Lisa’s Experience*

Lisa’s transition experience has been affected by her EBD and the diagnosis itself. Overall, her diagnosis has had a positive impact on her experience, particularly in the way she sees herself. Five central themes are evident in her narrative, including: 1) Impact of Diagnosis and Treatment on Self Concept; 2) Issues Regarding Medication; 3) Impact of EBD on Self and Construction of Reality; 4) Impact of EBD on Relationships; and, 5) Impact of Transition and Academic Pressures on Anxiety.

*Theme One. Impact of Diagnosis and Treatment on Self Concept.* Before she was diagnosed, Lisa had an “intimation there might be something wrong,” in high school but did not seek assistance and was “still functioning and raised with this whole self-reliant thing I can’t get over.” She decided to go to the counseling center shortly after attending

college because she was “crying all the time and really depressed.” When she was diagnosed with generalized anxiety disorder (GAD), she was:

Actually really excited because I felt like there was something wrong with me. So when he said that (she had GAD) it made me feel hope. I have a disorder and they can help me. I don't have to hate the way I think forever. So it was a big relief to me, especially when it started working. I was a whole new person for a little while (with laughter) I was so HAPPY. I felt like a whole weight had been lifted.

After the medication started working she realized she had been experiencing anxiety all her life “but didn't know what it was...I didn't know what was wrong with me.”

Being diagnosed with GAD, as well as medication and therapy, also changed the way Lisa felt about herself:

The diagnosis probably changed the way I think about myself because before that just hated myself. I just hated the way I think, the way I would talk, everything about me. I hated it; I hated myself, the way I thought. Everything I did I hated. I thought that was normal. I think the fact that the anxiety was the dominant feature in my personality, and I hated that so much because it got in the way of what I wanted to do and I was always afraid of things. Also, I have personal narratives that are pretty much constantly nattering at me, so that's what I tend to think of as myself, that narration. And so the narration tends to be annoying to me, umm, because it (long pause) first of all I can't stop it. Second, it tends to be sometimes two things going on; it's really confusing. So I hate that. And now I see that narration as the voice of my disorder. So I think the diagnosis helped me



understand that I wasn't hating myself; I was hating my anxieties, so it helped me kind of, love myself (with laughter), kind of embrace who I am as a person, because I was able to separate myself from my anxieties, because I am not them. And it felt good, because I didn't want to be that person, I didn't want to be scared and neurotic. I wanted to be what I was projecting but didn't know how, that is how the drugs and therapy helped me.

She still experiences symptoms of anxiety but they are not as acute and she has a better understanding of how to deal with them now. Therapy has been very helpful for Lisa:

It (therapy) is actually an integral part of my system of trying to overcome my anxiety because I don't talk to people about things and it tends to end up, like I just had, right before fall break I had a major breakdown right before class. Instead of that kind of emotional breakdown, I'm able to work through some irrational thoughts (with laughter). I get to get out the crazy a little bit with the therapist, and he helps me when I come in with these kind of irrational everything is going wrong in my life, and I can't do anything right and my over-emotionalized feelings. He helps me work through where they come from, and why I think them, and haven't I thought them before, and didn't it turn out okay, and we talk about not reading minds, you know, and that kind of thing.

Both medication and therapy have allowed Lisa to ask for help from her friends, family and others:

That used to be a much bigger problem, but the meds and the therapy are kind of helping me set up a new structure of how to you know, being okay, I used to not

be okay with asking for help. If I couldn't handle it, that was my deficiency, so I kind of gotten to this more mature way of thinking about things. "Okay, it's alright to ask people (for help)," but I still, I definitely take more on myself than I ought to. I still get lost in that kind of way of thinking, but therapy kind of helps me realize its okay to ask.

*Theme Two. Issues Regarding Medication.* While Lisa recognizes that therapy "has been a great help," she believes "the major breakthrough was going on medication, and realizing the way I think can be changed that easily because that was a revelation to me, and then I became open to the idea of therapy." Although Lisa credits medication as changing her understanding of herself and helping her realize she has a problem, she has had a lot of issues with meds. At first, I felt like a whole weight had been lifted, but it came back." Lisa:

Started out on Zoloft, which changed my life, but there is a side effect, which was depersonalization disorder, which was creepy for me. I am so used to being worried about things all the time, but when it hit me I didn't notice, and then I realized I would be like sitting on a perch and not thinking about my movement. Which is strange, because danger is always in the back of my mind, so that scared me a lot. So I think I recognized that. I haven't had that happen to me since Zoloft. But I think if it was happening, I'd be able to control it more (with laughter).

Another side effect that Lisa experienced with Zoloft was anorgasmia, which she also experienced when on Paxil. “Then I was on Wellbutrin. It wasn’t enough. I’ve had so many meds it’s hard to keep them straight (with laughter).”

Lisa has been on medication for three years but stopped taking them last year and describes that time as awful:

I can’t live like that. It was (my decision) they had put me on so many different drugs, so I thought “they don’t know what’s wrong with me so I am just gonna stop.” I was on Cymbalta and it didn’t do anything for my anxiety so I stopped taking it. A medical doctor put me on it and Wellbutrin too which I think is funny now. It has really terrible side effects for people with anxiety. I had panic attacks, *everyday*. But when I am not meds, its worse.

Instead of taking prescription medication to cope with her anxiety, Lisa began using marijuana:

All the time...and I did all my work high I did everything so and I know that was bad, at the time, it seemed logical (with laughter). Smoking pretty much from (pause) I would smoke before class, after, it was almost constant. And it’s hard to keep that up because I mean it is chasing the dragon you never get what you’re really looking for. It was the way that I felt during that time, because when I was off the meds, I still needed something. And after a while, I understood I was just replacing pills with weed basically, and it wasn’t healthy or helpful to my academic career either (with laughter). I did fine, I passed...I didn’t fail a single class last year. I didn’t have any problems with professors, but I felt, cause it

didn't help my anxiety, it just gave me a break from them for a brief period, sometimes stronger, because there is that paranoid effect, but umm, I didn't want to be in a stupor anymore, because when you get to that point being high is the default setting and it's like being sober is being high. That all gets switched around it was making the thing that gave me kind of a relief into kind of another form of work, because I had to work hard to get money to get it, but it is not as satisfying because you've been smoking all day. It's just a weird cycle that probably every drug user gets into, but I knew that's not how I wanted to live, and I was just covering over things I should be working on, and I wasn't in therapy either that whole year. I don't even know how I got through that, it was so traumatic.

She “finally” decided to start taking prescription medication again when she was at home for the summer. “I went back to that doctor that put me on stuff (Cymbalta and Wellbutrin) that didn't work. She (also) put me on Klonopin and Ambien for sleep, kind of a cocktail because I cannot sleep without the meds, but that really didn't help. The medical doctors back home, they're kind of useless.” When the Fall semester began, she went back to the Counseling and Wellness center. Again, Lisa felt she “was at the mercy of the Western medical system” and tried a variety of “prescription cocktails...they put me on Remeron alone, and that worked for a while, but I had restless leg syndrome, they said there wasn't anything else they could do, so they put me Trazodone,<sup>22</sup> which made

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<sup>22</sup> Trazodone is a generic medication used to treat depression, anxiety and panic disorder.s

me feel weird and gave me RLS. Then they said you need to be on Klonopin, so I take that with Remeron.”

Lisa is somewhat ambivalent about taking medication because she feels they help her but is concerned about taking medication for the rest of her life. “They don’t know what the side effects are; there is a problem with memories with benzos, so that is something to worry about.” However, she feels they are a necessary element of her treatment:

It (taking medication) is just something that has become a part of me...that I don’t (pause) just the other week when I saw the psychiatrist, I told him about the RLS, and he (pause) was like “I have nothing left to give you,” and that was really frightening for me because I remember what last year was like, how hard I had it. Just making it through the day without having anything to help me with my anxieties, and I got lost in my own stupid problems. I was worried about that happening again, so when he said that it upset me and I cried, “you have to have something” and I knew Klonopin helped me, but they were leery about putting me on it because of the abuse potential. And that is something I worry about too. Do I want to be on meds for the rest of my life? I’ve come to terms with that, existentially as a person, I think.

Currently, Lisa takes 1 mg of Klonopin, 15 mg of Remeron and smokes marijuana

“about” twice a day, “at least.” She says they all help in different ways:

Remeron makes me not notice what I was doing; there is a reduction of anxiety.

But it’s not what I really want, which is an eradication of anxiety. The Klonopin

helps me relax and sleep a bit. I use marijuana to let me get a break from the narration, the constant nagging voice. I thought the Klonopin, the Remeron, the Zoloft would help, but nothing stops it (the nagging narration). Some things do slow it down, but it is such an intense experience all the time, I really run away from being cerebral and go get high (with laughter). That's my break, and that's the only time I get where I'm not analyzing myself, nagging myself, and hating myself all at the same time.

However, she is uncomfortable with her dependency on marijuana:

I don't like that I am dependent on that illicit substance, because it is just another source of anxiety. It is illegal, it's stupid too. It makes me feel stupid but at the same time; I don't know, I feel like I'm out of options because everything I've tried to do for myself to overcome it has not worked. What it's really effective for getting me to do is getting me to break off is that cerebralness that comes off all the time that you just witnessed. So I take a refuge in being stupid for awhile. I know it is temporary and I know it is going to come back so I tend to get anxious even when I use it. I used weed all the time last year when I was off the meds, and it was terrible, so I learned my lesson. I don't drink, I don't enjoy alcohol. I don't have that outlet that most people do, to go on a binge drink to release stress. I don't find that appealing or enjoyable, so I smoke (with laughter) to get away from myself. Maybe I'll replace it with something else someday, but I don't know what that will be.

*Theme Three. Impact of EBD on Self and Construction of Reality.* Lisa's anxiety has impacted her sense of identity and how she projects herself to other people. She feels that "There's not a unified individual person that I think of me, I kind of have all these different, I think of it as degrees, like a spectrum kind of thing. Lisa is here, and Lisa goes over here. I don't have a central 'this is me.' I have narratives going on in my head. This is so hard to explain (under breath)." She question who she is and describes herself:

At war with her ego (pause) because I have that narration that kind of serves as a unified self most of the time that I don't, I don't actually consider myself. So I don't know who I am. I don't have any idea of which traits are actually mine, and second, I just, I hate the one thing that could be the unified me, the anxiety (with laughter). I don't like how my brain works; I have these fantasies of getting rid of it.

Although Lisa is constantly thinking, there are aspects of her "narration" that she finds useful. "I don't mind the philosophical kind of things that get thrown out there, and it helps me to be analytical and thoughtful. But, it's the nagging. So when I say I hate myself, all I mean is that I hate that nagging voice, that voice of the anxiety."

One of the ways Lisa deals with her anxiety, her "constant narration," is to create, and project, different personas:

I feel like I'm constantly, this is Nietzsche, I feel like I am constantly overcoming myself in terms of that narration of anxiety, so there is a lot of running away from me, which is probably where personas come it, because I don't like the person I think I am. I tend to think of myself of falling apart constantly or having

breakdowns, that's how I think of myself, a neurotic mess, and assuming that is what I project to people, but I guess it isn't.

Because she saw herself as an "anxious neurotic person," she:

Pretended to be someone else (pause) I did this persona thing, I am this other person who can handle things. But on the inside I am thinking about how scared I am in these situations. When I talk to people they say I seem on top of things, but that is not how I feel. There is a difference in how I am perceived and how I see myself.

Lisa also believes she needs to project a certain image of herself because she feels that other people:

Are better than me, and then I compare how I feel about myself to how I perceive other people who are projecting just like they are projecting. I forget that they may be falling about too, and that's a problem. Because I assume they are putting out who they are. And I think they are always together, always prepared, but that might not be true. I forget that other people have internal lives, just talking to people about that helps more than anything.

*Theme Four. Impact of EBD on Relationships.* Because Lisa created a persona for herself, she felt a distance between her and her friends and family:

I got in the habit of being detached emotionally, and not knowing how I was feeling, just projecting how I was supposed to be feeling, so I was hiding and the lying to people I cared about, with my parents they had no idea that I was really depressed and all sorts of people didn't realize what was going on. I feared being



thought of as weak, and inadequate, and somehow the fact that I had anxieties about that seemed to increase my inadequacies as a person, so I hid it. So people don't think about me as an anxious person, because I hide it and internalize it instead of me acting out and being needy and always having to be the center of attention, so I can it could be expressed in alternate way, I just put it on myself, not on other people.

When she did disclose her GAD with her friends and family, they were surprised because she was able to hide it well, "for the most part."

Although most people were surprised, they did not respond negatively. "I actually haven't had a negative reaction, except from my parents, people are surprised, but nobody seemed to think it is a big deal. I think our generation is so used to being prescribed thing and having things that most people don't react negatively." Her parents did have a "bad reaction" when Lisa disclosed her diagnosis and that she was taking medication:

When I called and said, "Dad, (with a sigh) I have GAD and I'm going on Zoloft," They were kind of like "What? Where is this coming from?" Because I had been lying for them for so long (pause) my mom, for awhile, thought it was a personal insult to her, which was strange for me. "I feel so much better, why are you so upset with me?" That whole year was me having to convince them that there was something wrong with me.

She was troubled by her parents' reaction and their disapproval:

At the time it felt like it was really painful to me that they didn't believe there was this thing wrong with me, but after I understood I had kind I had completely contributed to that, by pretending everything was fine and not letting them know what was going on and I blame them for having me do that but that wasn't their intention. They wanted me to tell them things but the anxiety got in the way for me. That reaction was the one I think about when you asked. How my parents...took it really personally was insane to me.

Lisa believes that she did not confide in her parents sooner because she felt pressure to “maintain a level of normalcy. My parents caused a lot of anxieties, but mostly I lied to them.” It was important to Lisa that her parents understood why she is in therapy and took medication:

I just had these discussions where I was telling my mom I made a persona, but that I was lying to them a lot, and I had a lot of anxieties. I told my parents that, making them come to terms with the fact I did lie to them my whole life. Making them think I was okay because I thought they wanted me to do. I don't know which came first. That's how I won them over I think.

Lisa feels that understanding her GAD and disclosing her diagnosis has had a positive impact on her relationships. She is now able to “open up to people better. I am not going to say I am good at, but it is easier to express myself than it used to be so that makes me more comfortable in my friendships and I reveal things about myself now.”

This is especially true for her intimate relationships:

My issues in dating are that I don't, I don't tell the person what's wrong, they ask and I say "nothing," because usually I am blaming myself for whatever is wrong, so I think I've gotten maybe a little past that. That's probably the sticking point when we would have arguments, I would shut down. With my current boyfriend, we are solid, he knows everything about me, which is comforting; it makes me feel like I can be myself. So that's been an improvement in relationships, me sort of opening up; I'm still not good at it. I tend to distance myself from it and kind of analyze what is going on, so that takes time, and it is usually about 20 minutes him saying something, me maybe responding, maybe not, like I don't want to talk about it is usually the extent of it, so I am trying to work on that, I guess it takes practice and we don't argue a lot (with laughter). It is a good thing.

Lisa has also found that she has become a better friend, and that is she is more understanding. "I'm much more compassionate person too; I don't know necessarily what other people are feeling but now that I've started to understand myself a little better I think I am better able to read social situations in a way I wasn't able to before. (I am able) to be more empathetic to friends and notice if there are doing the same things I do." She also "gives more" in relationships because she is more comfortable talking about herself:

(I am now) less afraid of putting myself out there because I thought people would think less of me and wouldn't like me if they knew the real me so I just internalized it and hated it and pretended everything is fine. Now that I've gotten past that I can be a real friend, in which you put something into the relationship instead of just solving their problems.

*Theme Five. Impact of Transition and Academic Pressures on Anxiety.* Lisa did feel anxiety and stress during high school, but was able to manage those feelings. However, when she started college, her anxiety became more “acute” and difficult to manage. “When I got here it just broke down, keeping everything under control was impossible. But I hadn’t realized before I could do anything about it. I thought there was something wrong with me. It was so, like acute, the anxiety that I kind of lost it.” Both the transition from “a stable environment” into one of more freedom, and the academic pressure amplified her anxiety:

It probably had a lot to do with the academics. The quality of education is soooooo rigorous and intense that when you first kind of come into contact with it you feel inadequate. And that is how I felt. I felt like I should be like all my friends, they were having fun. All these people just loved it here, and I was crying and having panic attacks.

She felt isolated and incapable of handling the academic load:

I was always calling my boyfriend from back home. “I hate it and I’m sad, and I don’t know what’s wrong with me, and it’s really hard too.” Something that just kept coming back, I don’t think I’m smart enough to be here. I had this whole anxiety issue about not being good enough to be here. I had all these expectations. I was projecting, “You have to do well, get them to like you. Be a perfect student.”

During her second semester, one class was particularly challenging:

I was in this class with eight guys who I don't know that make the level of discourse so incomprehensible to me that I couldn't understand their questions, the professor was great, she made sense to me, but when they talked, I felt an insane amount of anxiety because I couldn't understand what they were saying, and I wanted to contribute but I couldn't because I had nothing to say, and I was so paralyzed in that class.

She says that experience made her feel "inadequate" and question her choice of majors.

She did not disclose her EBD to her professors or ask for help because:

It (disclosure) doesn't occur to me, its, my diagnosis was relatively recent in terms of my life span. If I have to excuse myself to somebody, like with the professor, just say "I have a disorder," that makes me freak, so my professors don't know, I haven't even told my advisor, laughs, that I have a diagnosis.

Ummm (pause) I tend to think of those as excuses; I didn't want to say that because a lot of times kids lie and make up really good stories about meds but it is usually a lame excuse, so I my fears kind of keep me from telling people about my fears (with laughter), and I don't want to be thought of as somebody who wants a cop out, sad. I've gotten over that a little bit, but usually with authority figures I don't talk about it.

She does regret not telling her advisor, who she thinks would have understood and helped her, but again, her anxiety prevented her from disclosing:

My social anxieties were so intense that I was assuming that if I did tell her that's what she was going to think of me; I'm just another student with an excuse, and

it's not even a very inventive one. So I don't I don't think it matters in the long run that I didn't tell her and she doesn't know, but it might have helped me last year. I could have maybe talked to her more.

Lisa credits her current success in college to both her will and being diagnosed with GAD:

Maybe the way I had to deal with my anxiety, for so long, made me a stronger willed person who could not give up when it seemed impossible, because there were moments when I thought everything was over, you know, my whole college career was ending. I think a lot of it was the diagnosis and being told it was not my fault, because I think I would have turned on myself and maybe committed suicide or something like that. Also, a lot of it has to do with my personality and why I continue to fight, I want to prove myself wrong all the time. I am constantly telling myself that it is not going to work, that I am not going to succeed, and people are much better than me, and there is no point, but something else kicks in. I don't know how to start, but I am trying. That is what has kept me going. In college, when I didn't know what I was doing here, I just kind of boot strapped my way up, this is my choice.

### *Impressions*

Lisa's transition experience can be understood in several ways. Primarily, Lisa internalizes her anxiety, which affects how she views other aspects of her life. Another important element of her transition experience is how she has adopted a philosophical framework in order to process and understand her anxiety. Finally, Lisa is aware of how

anxiety affects her life and is working toward making positive changes in the way she manages challenges related to her EBD.

*Internalization of Anxiety.* Lisa's internalization of her anxiety is a salient feature of her transition experience. She describes her anxiety as an "inner narration, the closest thing I have to a unified self." While she does separate "Lisa" from the "voice of the disorder" and accepts herself more, she still feels controlled by that "inner dialogue, the constant nattering I can't get away from (pause) that is constant. I am constantly trying to undermine it or get away from the narration. So there is a lot of running away from me."

In some ways, Lisa feels that she has been controlled by her anxiety. "I had been inside this box my whole life. I don't like how my brain works; I have these fantasies of getting rid of it." Further, she has created a persona that allows her to "pretend" and seem "normal," and that is different than "who she really is...people don't think about me as an anxious person, because I hide it and internalize it instead of acting out and being needy." Although she has become more open about her EBD and has sought treatment, she is still hesitant to share her diagnosis, particularly with authority figures, because she does not want extra help or "to make excuses." "I take personal responsibility with everything, and that is really important to me. So if I say I have a disorder, I feel like I am giving an excuse whenever I say it." She is also cautious about disclosing her EBD because she is concerned about what others think of her, and feels the more she shares, the less control she has:

I still have that kind of thing that I express a lot when I don't talk about my emotions immediately and I wait for me to figure them out; its not here's what

I'm feeling, analyze it yourself, I always have to be in control of what they are perceiving of me, I am trying to get away from that, but that is the hardest part, not being in control of how I am being perceived, which is pretty pathetic (with laughter).

Lisa also focuses so much on her anxiety, on her failings that she forgets that other people may have challenges or doubts. "I tend to think of myself as a...neurotic mess...I forget that they may be falling about too...I forget that other people have internal lives."

*Use of a Philosophical Framework.* Clearly, Lisa spends a great deal of time thinking about her EBD and develops "anxiety about the anxiety." She has adopted a philosophical framework in order to help her process and understand her GAD. Specifically, she talks about Nietzsche's conception of the will to power and overcoming. "Nietzsche talks about when you impose your will on yourself, you overcome. So I tend to challenge myself. I feel like I am constantly overcoming myself, in terms of that narration of anxiety." This framework gives Lisa a way to understand how GAD impacts her life, as well as a way to manage the effects of her anxiety:

The thing I said about overcoming, I do that all the time, because I have anxieties about everything, like I had an anxiety about coming here to talk to you, I had an anxiety about going to class today, you know, but it tends to work out okay, so I have this process of like, fear pushing me to do what I need to do, and then feeling a little bit of freedom of the will that Nietzsche talks about when you impose your will on yourself, you overcome.

This framework enables her to understand her challenges and how to manage them.



*Process of Change and Growth.* Lisa demonstrates an awareness of her EBD and a desire to manage and/or change behaviors that negatively impact her life. Lisa has accepted her diagnosis and treatment, as they gave her a way to stop “hating” herself. Throughout the interview, she used terms she has learned in therapy, such as “automatic thoughts,” “insides to outsides,” and “emotional reasoning” to describe how she reacts to situations. She views therapy as a “place to figure out the aspects of my personality I can’t change, and the ones I can, like habits I created to deal with my anxieties, (such as) automatic thoughts.” Some of her automatic thoughts include thought of failure, being judged, that everyone else “has it together and isn’t a neurotic mess.”

However, she was resistant to what she was learning in therapy, “It really did take my therapist... I kind of hated him for a while, because he would come up with the automatic thoughts thing, and I was like ‘shut up, I don’t want to hear that, it is true, and my emotional reasoning or whatever’... and sometimes when he reminds me of something, like I don’t know what other people are thinking, I’m like ‘I hate you’ (with laughter).” She credits therapy as “essential” to her success in college and sees herself “More complexly, probably, like somebody who is constantly working on herself... I’m teaching myself, rewiring my thoughts (pause) all the time.”

#### *Composite Themes*

Although each of the participants’ transition experience is unique, several recurring or overlapping themes are evident, and can be categorized according to the research question they address. Themes relating to question one, which explores the experience of being diagnosed and living an emotional disability, include the impact of

the EBD on the self, feelings of ambivalence towards the diagnosis, issues regarding medication, the impact of the EBD on relationships and interactions with others, and the continual struggle of dealing with an emotional or behavioral difficulty. Question two addresses how having an EBD impacts their transition experiences and their ability to achieve their goals; relevant themes include academic challenges, issues regarding seeking assistance, and their selection of career choices. Question three examines the role of supports and assistance during their transition experience. Prevalent themes included medication, formal and informal support systems, and suggestions for additional supports to assist emerging adults with emotional or behavioral disorders. Finally, additional themes arose from the research that do not correspond to the questions, such as personality characteristics, the development of coping and management strategies, and a desire to help others.

*Question One: How do selected emerging adults perceive and describe the experience of being diagnosed and living with an emotional or behavioral difficulty?*

As previously stated, each of the participants' transition experience from adolescence to adulthood is different. However, the participants' descriptions reveal common elements of their experiences, such as the impact of having an EBD on their self-concept, their feelings regarding their EBD, issues regarding medication, the impact on relationships and interactions with others, and their continual struggles managing their EBD as they work toward their academic and vocational goals.

*Theme One. Impact of EBD on Self-Concept.* When describing how their EBD affects how they see themselves, most of the participants were self-critical, questioning

their ability to cope with their problems, Tara describes herself as “a sensitive person and hard to deal with at times,” and not able to “handle things well.” Beth becomes “severely depressed” when she fails an exam, which makes her think about her “self-esteem.” Kristi blames herself for her anxiety, “I make those things (problems for myself); it is really me.” Lisa thinks of herself as “falling apart constantly... a neurotic mess.” Because she was unhappy with “who she is,” she created another persona. “I am an anxious neurotic person, (So) I pretended to be someone else.”

Furthermore, participants often compared themselves unfavorably to other people, wishing to be like other people, “who have it all together.” Kristi wondered “what was wrong with (her)” because she was unable cope with her anxiety compared to a friend. Almost all of the participants expressed a belief that a lot of other people do not experience the same difficulties. According to Dani, “it is a little harder because they don’t have to make the same choices as I do, they don’t have to constantly think it.” Having an EBD has impacted the way the participants feel about themselves because they question their ability to cope with their challenges, particularly compared to other people.

*Theme Two. Feelings Regarding their Diagnosis.* Most of the participants expressed ambivalence towards their diagnosis. All of them described learning of their diagnosis as a relief, and that it gave them hope that their lives would improve. Dani remembers thinking, “Okay, I am not crazy for always being sad. There is actually a chemical thing going on, and there is a way to treat it.” Beth was “actually relieved that it just wasn’t me, and they had a name for it.” Tara echoed the same sentiments, “It was a relief to know I wouldn’t have to live with that anymore; it was nice to have a name to

what I've been going through." She also believes that the diagnosis helps her understand herself and her behavior. Lisa felt excitement and hope when she was diagnosed with GAD. More significantly, her diagnosis changed the way she thought about herself:

Before the diagnosis, I just hated myself. I think the diagnosis helped me understand that I wasn't hating myself; I was hating my anxieties, so it helped me kind of, love myself (with laughter), kind of embrace who I am as a person...because I was able to separate myself from my anxieties, because I am not them.

Although the participants were relieved when they were diagnosed with an EBD, several of them expressed ambivalence and recognized a "downside" to their diagnosis. Being labeled makes Beth "feel lower" because now "I am a disability, or I'm on the disability list." Tara discussed the stigma that comes with being labeled, "a lot of people have misconceptions about it." Dani wondered if the "diagnosis (of bipolar) really fit" because she does not have "all the symptoms" and doesn't feel like a "typical case." Kristi feels that she has "become a special needs person." The label does not bother her because "I knew something was wrong" but living with GAD is "kind of bothersome...it's very hard." While all of the participants felt relief when they were diagnosed, and felt "hope" that "things would get better," they faced challenges finding beneficial treatment.

*Theme Three. Issues Regarding Medication and Therapy.* All of the participants tried medication, with varying degrees of success. Two participants, Beth and Kristi, have stopped taking medication. Although Beth was originally "excited" to start taking

medication, nothing “worked” except Lexapro, but she stopped taking it because of the side effects, “he tried a lot of things but they didn’t work; it was all trial and error. I finally gave up.” Kristi also tried a lot of medication but did not experience long lasting benefits. “Remeron made me a zombie; Paxil worked for awhile and then stopped. Se tried some other stuff (pause) I kind of gave up on it.” Lisa, who is taking a “cocktail” of Klonopin and Remeron describes feeling like she was “at the mercy of the western medical system, I got bounced around from medication to medication for awhile.” Dani has also been on numerous medications, “there were a lot of trials before they finally found what worked.”

In addition to having difficulty finding the “right” combination of medications, several of the participants expressed ambivalence regarding taking “a pill” for the rest of their lives. Lisa believes that Zoloft changed her life, and that taking Klonopin has helped her, but “they don’t know what the side effects are; there is problem with memories with benzos, so that is something to worry about.” She also wonders if she wants “to be on meds the rest of my life.” One of the reasons Beth stopped taking prescription drugs was the idea of taking them for the rest of her life. Dani wonders how taking medication has affected her identity, “There is always this confusion, like, am I who I am when I am on medication? So that is really confusing, and it is hard to form a self-identity I guess.” All of the participants expressed concern about the side effects, but Lisa, Dani, and Tara, who are still taking medication, believe “it is worth the risk.” All three stated that close friends and family members have noticed a difference in their moods and behavior. In fact,

Dani's dad "insists" that she take it, "he says, 'I love you, but you are so much better (to deal with) when you are on your meds.'"

All of the participants have tried some type of therapy, but again, with varying degrees of success. Only Lisa and Dani are currently participating in therapy, which is required in order to receive their prescriptions from their college counseling center. Both of them find therapy beneficial, particularly Lisa, who finds it to be a "great outlet." Tara's parents "forced" her to go to therapy when her mother discovered her cutting marks, but she "didn't want to talk to them." Now, she believes the medication is enough, and does not need therapy. Beth found it helpful in some ways but did not want to "start over" with another counselor when hers left. Also, she believes she can "handle it," and doesn't see:

Were else someone can help me. Honestly. If anything, they will just try to feed me meds again. Or try to get me to develop my feelings. Is that going to do any good? Am I still going to have panic attacks, and school will still be hard.

Kristi has experienced a lot of "issues" with therapists, particularly with the two therapists who also treated her mother. She felt it was "awkward," and more about her mother than her. In addition to the effect of having an emotional or behavioral difficulty on their self-concept, their feelings regarding the diagnosis, and the challenges of finding useful treatment, the participants' relationships with other people have also been affected.

*Theme Four. Impact on Relationships and Interactions with Others.* Living with an emotional or behavioral difficulty has impacted the participants' relationships and interactions in a wide variety of ways, negative reactions from at least one parent when

they disclosed their diagnosis, and the participants struggle with “opening up,” expressing their feelings with their friends and family, and concern about how others may respond to them.

All of the participants described initial resistance from at least one of their parents when they disclosed their diagnosis, but most feel that their parents have come to terms with their diagnosis and treatment. Dani’s father “completely accepted it,” but it took her mother a “long time to accept it...it was an issue.” Tara went to her doctor by herself when she turned 18 because her mother “blew off” her feelings of depression when she was 14, but finds her mother is “totally supportive” now. Beth’s father also “didn’t take it seriously, until he actually saw me breakdown and said ‘this is real,’ so he bought me a book (with laughter).” At first, Kristi’s mother “kept saying ‘no, no, no, you are not like me at all,’” but is now on the “bandwagon and says, ‘we’re just alike.’” Lisa found her parents “bad reaction” troubling; they “took it really personally (and that) was insane to me.” When asked why they thought their parents were so resistant, most of the participants admitted that they “kept everything in,” or “didn’t want to discuss it,” or “pretended everything was okay.” Lisa says she finally “won them over” when she convinced them that she had been “lying to them” her whole life.

Many of the participants believe their parents were surprised by their disclosure because they did not talk about their challenges or “kept a lot of things in.” Indeed, all the participants expressed difficulty sharing their feelings and often becoming “emotionally distant.” Beth rarely discusses her challenges or anxieties with her family and friends, “My problem is I kept everything in.” She chooses not to share her anxieties because she

does not want to “burden” her friends and family. Before Lisa began therapy, she “got in the habit of being detached emotionally and just projecting how I was supposed to be feeling, so I was hiding and lying to people I cared about.” Therefore, she understands why her parents reacted the way they did and why her friends were surprised when she told them she was diagnosed with GAD. Tara also expressed difficulty expressing her feelings, “I couldn’t really talk about it.” Currently only her mother, boyfriend, a couple of close friends who found out “accidentally” know she has been diagnosed with an EBD. “I just don’t know how to bring it up...it creates some distance.” Kristi has difficulty expressing her feelings because she does not “want to be vulnerable.” Also, she does not “like to confront people; I would rather deal with it on my own than have to worry about what would happen. I don’t want to put myself out there to get hurt more.”

Many of the participants are also reluctant to share their diagnosis or their emotions because they are concerned about the reaction of their friends and families. Beth does not like to tell her family “what is going on” because “they are worriers...and I don’t want to upset them.” Both Kristi and Dani believe that people dismiss their thoughts and feelings because they have an EBD. Lisa also expressed concern regarding the way people would perceive her, but for different reasons, “I feared being thought of as weak, and inadequate, so people don’t think about me as an anxious person, because I hide it and internalize it instead of me acting out and being needy.”

*Theme Five. Continual Struggle.* Finally, although the participants feel they are working toward their goals and are “managing”, they describe the experience of living with an emotional and behavioral difficulty as a “continual struggle.” Beth recognizes she



will “never be cured; it’s not like I overcame it. I still suffer from it; even today I had an attack. But what can you do? I go to the gym; I find ways to manage.” Indeed, managing her anxiety “Is a daily thing, something I always have to think about.” Lisa feels that she is “constantly overcoming herself,” and describes herself as “somebody who is constantly working on herself, I’m teaching myself, rewiring my thoughts (pause) all the time.”

Dani views her experience living with an EBD as a “continuous choice between following her treatment plan and being normal.” It is something she thinks about and manages daily. Although Kristi is in a “loving, supportive” relationship and has recently graduated, she acknowledges that her anxiety and stress “are a constant battle.” For Tara, “things are much better now that I am on medication.” However, she still has trouble sleeping and concentrating. “Sleep is still a huge issue for me. It’s a challenge to fall asleep at night and stay asleep. It’s a challenge not to get too stressed out.”

*Question Two: How do selected emerging adults with emotional or behavioral difficulties perceive and describe the impact of their EBD on their transition experience and ability to reach their future goals?*

Although all of the participants are working towards their goals and are determined to achieve them, having an emotional or behavioral difficulty has impacted their transition experience as they work toward their academic and vocational goals. Prevalent themes include academic challenges, disclosing their EBD to professors, and career choices.

*Theme One. Academic Challenges.* The participants discussed how their EBD presented academic difficulties. Dani feels that she can “accomplish more” when she is

not on medication and is now having to “re-learn” how to study and complete assignments the way “other people do.” Tara has trouble focusing and concentrating on reading because of her anxiety, “I couldn’t get into reading stuff, and I forced myself to do it but it was very hard, and I always procrastinated, always. But I had to do intervals when I would read and it was very hard to concentrate.” Both Kristi and Lisa struggle with perfectionism and not being “good enough.” Kristi’s desire to be perfect increases her anxiety. Lisa believes her anxiety became more acute and difficult in college because of the pressure she felt. “I was projecting, ‘you have to do well...be a perfect student.’” Although Kristi, Lisa, Dani and Tara experience academic challenges, they all “end up doing fine” in school, and have not failed any courses. Kristi was concerned she would not finish her portfolio on time, but did successfully complete that project. Beth, however, did fail one course and withdrew from two others before she sought assistance from the Office of Student Disability Services. Her grades have improved since she began receiving accommodations from the Office of Student Disability Services however; she still becomes anxious during exams or certain classroom environments.

*Theme Two. Disclosing their EBD to Professors.* All five of the participants feel uncomfortable sharing their diagnosis with professors or other “authority figures” because they are concerned about how they will be received or that the professor will just dismiss their challenges as an “excuse.” However, three of the participants have disclosed that they have an emotional or behavioral difficulty to their professors because they felt they had “no choice.” Beth has experienced the least discomfort because she recognizes

how beneficial it is. However, she does worry about the way her professors perceive her and is “always calling and explaining...I don’t want them to think poorly of me.”

Although she is concerned about how her professors may view her, she recognizes how helpful many of her instructors have been, particularly her math professor, who tutored her individually for a semester. Kristi’s has also discussed her EBD with two professors because she was “way behind,” but was uncomfortable. “I don’t like to openly say I have a disorder because I don’t want them to feel sorry for me, and I don’t want to feel like. Personally, I don’t want to feel like I am blaming everything on that.” However, they “were helpful.” Although Dani has also found her professors to be helpful and “really understanding” when she talks to them about her bipolar disorder, she does not like to ask for help because she does not want to be considered “weak.”

Neither Tara nor Lisa has disclosed their EBD with their professors because they do not want their professors to “pity” them or think they are just giving an excuse. Tara thinks it is “okay for other people, but I see it as I am using it as an excuse.” Lisa feels that disclosing that she has “a disorder” would make her “freak.” She also sees it as an “excuse,” and doesn’t want “to be thought of as somebody who wants a cop out. I’ve gotten over that a little bit, but usually with authority figures I don’t talk about it.”

*Theme Three. Effect on Career Choices.* Living with an emotional or behavioral difficulty has impacted the participants’ career choices, albeit for different reasons, including academic concerns and, an enhanced desire to help others because of their own difficulties. Beth originally wanted to be a surgeon, but is now considering a career as a Physician’s Assistant:

I am now looking into P.A. programs in Orlando... I'm always in between medical school (or a P.A. program), (med school) is four years plus residency whereas P.A. is only two years, and I am thinking those last two years I can be free of school; I am thinking it would be too much.

Although Lisa has not changed majors, she has considered it because she often feels "inadequate" and "unsure" in her classes. Tara switched majors from pre-med to communication science disorders because she would "get stressed out easily" and become "frustrated" in chemistry. "

A desire to help others was a factor for most of the participants when they were choosing their career paths. Dani, Beth, Kristi and Tara have all selected careers in which they can "help others." Beth is "insistent" on remaining in the medical field, "I am going to work in a hospital, where I can help other people." Dani, who plans to work in the Teach America program for two years, believes that "Having bipolar has made me more sympathetic to others. Kristi is also motivated to teach because of her personal experiences, "I knew how difficult it was for me to deal with what I had to deal with, and then I found myself attracted to children that had needs, so I can relate and help them.

*Question Three: How do selected emerging adults with emotional or behavioral difficulties perceive and describe the role of supports that contribute, and those that could contribute, to achieving their desired vocational and educational goals?*

The most salient response to this question was that all of the participants have sought and received some type of assistance, with varying degrees of satisfaction. All of the participants have tried medication and therapy, and all currently utilize some type of

treatment or support, either formal or informal. Finally, the participants suggested additional supports that could contribute to successful transition.

*Theme One. Formal Assistance.* Although most of the participants struggled with finding the “right” medication, three of the participants are currently taking medication and find it helpful. According to Tara, “taking medicine really helped me as far as getting the sleep I needed and being able to concentrate on the work I needed to do. So as far as transitioning to college it helped a lot because of the anxiety of moving to a city and living on my own.” Both Dani and Lisa believe the combination of medication and therapy has been beneficial to their success.” Lamictal “generally works” for Dani and currently “everything seems to be good.” Lisa described medication as “the major breakthrough” because it helped her realize that her life could be different. She credits therapy essential” to her success in college “It (therapy) is actually an integral part of my system of trying to overcome my anxiety.” Beth receives accommodations from the Office of Student Disability Services which allow her to take exams in a private setting. In addition to utilizing the SDS, she has taken a study skills workshop offered at a local community college. These services have made her transition experience “much better... So I am very comfortable, pleased, relieved about it and it is showing in my exam scores.”

*Theme Two. Informal Assistance and Support.* Most of the participants rely on a support system comprised of family members and friends, who listen to them, provide encouragement, and give advice. Dani’s friends often persuade her to “get out of her room” when she is depressed. Because Tara does not attend therapy, her friends,

boyfriend, and mother are her primary means of support. Although she is reluctant to “open up” to people, she finds that the more she does, the better she feels about herself. “Their reactions have been understanding and helpful, so it has helped me become a better person too...more accepting of myself and of other people.” Disclosing her EBD to her boyfriend was “a load off” because it was “having someone who understands me.” She describes her mom as “rock, a shoulder to lean on.” Beth does not like to share too much with her family and friends, because they worry a lot, but knowing that they care about her and love her is very supportive. She credits all the support she has received for helping her reach her academic goals. When asked what has been the most helpful, she responded “I guess it is a variety of a lot of things. A little bit of everything...the counseling helped, the workshop helped, my parents support me; it is a community thing.”

*Theme Three. Suggestions for Additional Supports.* When asked what other supports may be helpful for adolescents and young adults, all of the participants discussed the need for mental health services in middle and high school:

I (Dani) think there should actually be like a voluntary counseling center for high schools. At my high school if they noticed that you, this happened to a couple of kids in my grade, that if they noticed you were depressed or cut marks on your arm, they just Baker Acted you instead of having someone talk to you. A lot of people are really ashamed about being upset about stuff so they won't tell their parents, they'll just ignore it. I feel like if you have a free open resource, ummm, people might be more likely to take advantage of it.

Tara and Kristi both talked about the importance of having a “real counselor” to talk to, because guidance counselors are busy “with schedules and other stuff.” Lisa believes that therapy should begin before college because “people get set in their ways, younger kids and high school students need help learning that it is okay to communicate their feelings and anxieties.” Kristi also discussed the need to make the process of receiving counseling services at the university a little easier. “I think that making the process to get supports a little less stressful would be beneficial because going to the tiny office with the big sign that says “student disability services” is a little intimidating.”

#### *Additional Themes*

The participants’ analyses revealed additional themes that did not correspond to the research questions, but are significant to their transition experiences. These themes include personality characteristics, such as determination and self-awareness, and the ability to develop and utilize coping and management strategies.

*Theme One. Personality Characteristics.* Throughout their descriptions, the participants revealed similar personality traits, such as determination, goal orientation, and high expectations for themselves. They described themselves as “motivated” and “determined.” Beth “knows” she “is persistent. I could have given up and my counselor made me aware that I could have went to drugs, alcohol, instead I went for help. I don’t drink or smoke.” Lisa is equally determined, “I’ll do whatever I have to do to make sure I do the best I can, regardless of any mental issues I might have. I’ll do whatever I can to make sure nothing gets in my way.” Tara “simply refuses to give up.” The participants say focusing on their goals helps them manage manifestations of their EBD, such as

anxiety, Kristi has “this strong passion to accomplish things. So when I’m getting to the point when I just don’t want to go on and I want to run away, I have to remember that I have to, it’s expected that I graduate from college.” Beth finds focusing on her goals a major source of strength. She taped her motivational card to her refrigerator to remind her why she “is going through all of this.” Dani also believes her drive and determination have helped her succeed “It’s a matter of choice, if you want something it makes it a lot easier to pursue it and go after it, despite everything else.” The participants also have high expectations for themselves; Dani “always take(s) pride in being able to take care of myself.” Beth also puts a lot of pressure on herself to succeed, “I get mad if stuff doesn’t go my way; I am really hard on myself...by the time I am so worked up I have to leave, I am depressed and am angry at myself.” Lisa’s goal is to earn a doctorate in Philosophy and states “failure is not an option for me, despite my anxieties and everything else.”

The participants also demonstrate self-awareness and self-advocacy. None of the participants were “surprised” by their diagnosis. Both Kristi and Tara “kind of expected it” and Beth and Lisa recognized their behaviors and “symptoms” during their psychology classes. Also, they all sought treatment on their own, despite their parents’ resistance or without their knowledge. Kristi tired of arguing with her mother, and “just made an appointment and went.” Tara went “as soon as (she) was legal. I didn’t think twice about it; I’m glad I did.”

*Theme Two. Coping and Management Strategies.* Although the participants vary in their utilization of formal treatment, they have all developed or adopted coping and management strategies to deal with their EBD. Tara manages anxiety by “listening to



music, watching TV, and giving herself breaks.” Beth learned many of her coping strategies from her counselor and workshop instructor; however, she continues to read and develop her own strategies. Her strategies are mostly positive, such as practicing “better” study habits, focusing on her goals, relieving stress through breathing exercises, praying, going to the gym, and getting involved in the community. Kristi describes her method of coping as “a whole lot just trying to relax, and calm down, and take one thing at a time.” Dani “constantly” researches ways to cope. When stressed or anxious, she finds ways to relax.” She also monitors her moods and medication, as well as the amount of sleep she gets, her diet, and her moods.

#### Overall Impressions

The transition from adolescence to adulthood for emerging adults is both a challenging and rewarding experience. For individuals with emotional and behavioral difficulties, the challenges are often intensified. Although living with an EBD is a “continuous struggle,” it also provides opportunities for feelings of success and empowerment. The participants are able to manage these challenges because of the supports they have received and coping strategies they have developed. Furthermore, their own personality traits, such as determination, belief in themselves, and goal orientation have been integral in their journey towards achieving their academic and career goals.

Having an EBD is not something someone “gets over;” it is rather something individuals live with and manage, often on a daily basis. It requires vigilance, and includes monitoring moods, behavior, side effects of medication. It also involves

managing manifestations of the difficulty itself, such as panic attacks, mood swings, insomnia, and feelings of anxiety. Living with an EBD also challenges one's sense of self for many reasons, including changes due to medication, coming to terms with the diagnosis, and symptoms of the EBD. Often, participants compared themselves to "normal" people and wonder why they cannot "have it together" like everyone else. However, participants were able to recognize personal victories, such as attending college and working towards their goals. Many participants expressed pride in not turning to drugs, alcohol, promiscuous behavior, or other destructive behaviors.

The process of diagnosis and treatment presents its own set of challenges, as it can lead to questions about identity or accepting that they "are labeled" or "different." It is also difficult for individuals with EBD to find the right medication, and they must undergo many "trials" before they find something that is beneficial but does not present unmanageable side effects. Some may give up on the process of using medication because they become frustrated. The idea of taking medication for their "whole life" is also troubling for many participants because of the possibility of long term side effects or the way it changes "who they are." Most participants explore other types of treatment, such as therapy. Some find it "helpful" because it provides them an opportunity to explore their issues, understand their behaviors, and "bring things to light." However, many stop attending because they are uncomfortable with the therapist, do not believe it is beneficial, or feel they can manage "on their own."

Living with an EBD also impacts interactions and relationships with others. Issues regarding disclosure are particularly significant. They do not want to be perceived as

“making excuses” or being weak. Participants are often concerned that their friends and family members dismiss their feelings and thoughts because of the EBD, rather than listening and validating their emotions. Social acceptance is also important for individuals with EBD because knowing someone else accepts and love them “as they are,” they are able to more likely to accept themselves. Furthermore, developing supportive relationships is central to successful transition. Most participants rely on their friends and family to listen and help them “work things through.”

Some individuals with EBD do believe their transition experience is more difficult for them as compared to others because they have to manage the manifestations of their disorder, as it is “another thing to deal with.” Many participants called their family or friends “back home” the first several months of college, crying and wondering “if they were going to make it.” Several participants find managing academic pressures challenging because they feel “anxious” or “stressed.” Some also deal with “perfectionism issues” and procrastinate and find it difficult completing assignments or studying. Again, disclosure is an issue because participants are reluctant to share their diagnosis with authority figures, such as professors, because they do not want to be perceived as “weak” or making “excuses.”

Developing coping and management strategies is a key aspect to successful transition. The participants all described ways they managed manifestations of their EBD, such as monitoring their stress levels and medication, exercising, taking time to relax and relying on their support systems. Also, the participants share personality characteristics such as self-determination, persistence, and goal-orientation. Their desire to achieve their

goals and “never give up” has helped them as they work toward achieving their academic and career goals.

### Limitations

It is necessary to recognize the logistical and philosophical limitations of this study. The sampling and screening procedures present logistical limitations. Although the research utilized criteria to select her sample, she relied on personal contacts to advertise her study. Also, the researcher chose the first volunteers rather than conducting a more thorough screening. The experience of the researcher is also a consideration, and the last interview yielded richer information than the first. Philosophically, the attempt to understand complex experience of individuals poses inherent limitations.

Phenomenological research is fundamentally a construction of a narrative in which there is always an incompleteness. This incompleteness is part of the inevitable complexity of this type of work. The ability to understand another person and their experience is always imperfect. It is also important to note that the data presented in this study is a co-construction between the researcher and participants in the study. Furthermore, the reader participates in this co-construction of the findings, deriving their own meanings and understandings.

## CHAPTER FIVE

### DISCUSSION

This study explored the experiences of selected emerging adults transitioning from adolescence into adulthood. Although research regarding the outcomes for emerging adults with an emotional or behavioral difficulty is overwhelmingly negative, revealing high drop-out rates, involvement in the criminal justice system, and low rates of employment, the participants in this study are experiencing favorable outcomes. Specifically, four of the participants in this study are working towards achieving their academic goals, and one has recently earned her Bachelors degree. The purpose of the study was to acquire a better understanding of the experiences of young adults diagnosed with an emotional or behavioral difficulty who are working toward their academic goals. Specifically, participants were asked about their experience living with an EBD, how their EBD affects their transition experience, and what supports or assistance have facilitated their transition process.

This research was framed in literature which examined the challenges and outcomes of emerging adulthood and transition, particularly for individuals with emotional or behavioral disorders. One of the goals of this study was to learn how certain individuals with EBD are able to work towards their educational and vocational goals despite challenges presented by their EBD and transition itself. The selected method,

phenomenological research, provided the participants an opportunity to share their individual experiences, and give voice to emerging adults with emotional or behavioral disorders. This chapter presents a discussion of the findings, linked to the research questions and the relevant literature, the factors affecting successful transition, implications for teacher education and practice, implications for mental health service providers, contributions of this research to the literature, and implications for future research.

### Review of Research Questions

The researcher explored three questions, asking participants to describe their experience being diagnosed and living with an EBD, how having an EBD affects their transition experience, and what supports have assisted them during their experience. One of the most salient aspects of living with a disability is the continual challenges it presents (Osgood et al., 2005; Vander Stoep et al., 2000). The participants described the need to manage the symptoms of their EBD on a regular basis. For example, Beth visits her classrooms before the beginning of each semester so she can decide where she needs to sit and determine how she will manage sitting in that room for the semester. Before each class, she spends time in car mentally preparing herself for the class session. When Tara has long chapters to read or is feeling stressed about a particular subject, she plans breaks ahead of time. Dani has developed a mental checklist in order to monitor and manage changes in her moods. The participants find that their challenges “never go away” and are something they must “constantly deal with.” Lisa described that she hears a “constant nagging narrative” in her head that she is unable to get away from.

According to Arnett (2006), emerging adulthood is an Age of Identity Explorations; it is a time when individuals clarify their identity. For young adults with an EBD, establishing a sense of identity is even more difficult (McGorry et al., 1996; Leavey, 2003). Dani questions “who she is” and wonders if taking medication has changed her identity. Lisa has created “multiple personas” to manage relationships and cope in various settings, such as work, school, and social situations. She also wonders if the “constant narrative” in her head is her unified self because she projects different personas. Most of the participants described a disconnect between the way others see them and how they see themselves, which make them question their identity.

Forming a sense of identity is an important aspect of developing a personal network of friends (Chickering & Reisser, 1993; Werner, 2001). Furthermore, it is often difficult for individuals with EBD to establish and maintain positive relationships. Both Dani and Kristi believe that their friends and family often dismiss their feelings, labeling them “dramatic” (Kristi) or wondering if they have taken their medication. Also, all of participants had at least one parent who was reluctant to accept his or her daughter’s diagnosis. Beth’s father “didn’t get it” until he saw her have a panic attack; Tara did not tell her mother she was going to see a doctor because she felt her mother “brushed her off” the first time she broached the subject; Kristi’s and Dani’s mothers did not believe they had a problem, and both of Lisa’s parents questioned why she was taking medication. However, all of the participants wanted their parents to understand, or at least accept, that they had an EBD. Despite the initial resistance, the participants feel that their parents are supportive and understanding. In fact, Beth’s father bought her a book about

anxiety shortly after seeing her panic attack. Both Dani and Lisa said they had “to work” to gain their parents acceptance, but were able to after long conversations and discussion. The participants also believe that their parents support and encouragement are integral to their success. Their need for their parents to understand highlights the significance of feeling accepted, and may lessen feelings of stigma<sup>23</sup>.

In addition to developing support and acceptance from family members, the participants identified people in their lives they turn to when they are feeling anxious or stressed. Dani discussed how important it is to have people she trusts to talk to when she is depressed. Most of the participants, with the exception of Beth, feel comfortable discussing their anxiety or mood swings with certain friends. Kristi, Lisa, Tara and Dani also rely on their boyfriends as a major source of understanding and acceptance. Dani spent “hours” on the phone talking to her boyfriend when she was not sure if she should continue therapy and taking medication. Tara said it was “huge” when her boyfriend said he understood and loved her when she disclosed having GAD. Although Beth is reluctant to share her concerns and feelings of anxiety, she believes that her parents and friends support and love her. Also, Beth works closely with the director of Student Disability Services, and discussed that she would not have been able to continue school without the director’s guidance. All of the participants agree that their relationships have helped them during their transition experience. Developing and maintaining relationships is often a challenge for individuals with emotional and behavioral difficulties (Holmes, 1995;

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<sup>23</sup> The issue of stigma will be addressed later in the chapter.



Davis & Vander Stoep, 1997; Leavey, 2003). The participants' ability to establish and maintain these positive relationships may be a key factor to their success.

Another important aspect of transition is the multiple changes the participants have experienced. According to Arnett (2006), emerging adulthood is also the Age of Instability. He describes this time as dynamic, when most individuals change direction in education, employment, relationship, and residence. Most of the participants expressed that they had some difficulties during high school but were able to "handle" them until they moved from home and/or started college. Lisa and Kristi "felt something was wrong" in high school but managed it by talking to friends or just focusing on their schoolwork. Beth did not feel anxiety until she began preparing herself for college, and then it became acute when she moved from home. Further, most of the participants discussed the challenges moving away from home and living independently. Lisa moved the furthest, from South Carolina, and discussed the many differences between her home town and her current setting, describing it as "culture shock." Beth described the loneliness and isolation she felt after moving from Orlando, and returns home frequently to work at the hospital she has been employed at since high school. Dani and Lisa also experienced feelings of isolation after leaving home. The participants also described the difficulties related to increased responsibility and need to rely on themselves. Kristi also discussed the challenges of living with roommates; one roommate left abruptly, leaving her "in the lurch" regarding the bills and rent.

Students with and without disabilities experience academic challenges when they enter postsecondary institutions (Arnett, 2006; Osgood et al., 2005). All the participants

described college as more difficult than high school, and several felt unprepared for the increased rigor. Lisa was surprised by how challenging college was for her since she had graduated from an International Baccalaureate program. Beth and Kristi discussed how easy high school was and that they have to work a lot harder to achieve “good grades.” Beth failed two courses and had to withdrawal from another because she was not “ready.” All of the participants described the need to study more. Many of their challenges may also be related to their EBDs. For example, most of the participants discussed how their perfectionism increases their anxiety, which often causes them to procrastinate or avoid studying or completing projects. Beth was diagnosed with GAD after she started college, and she believes it was “brought on” by the increased pressures and demands. In addition, Beth and Tara changed their majors because of anxiety related to particular courses and subjects. They were both pre-med majors but struggled with math or science courses. After much deliberation, they switched majors, and are satisfied with their decision. Although they experienced academic challenges, the participants found ways to adapt, either by switching to other majors, developing ways to relieve stress, or improving their study skills. Many students with EBD do not have the support or ability to develop and use coping strategies, particularly when they are in independent settings. The participants’ competencies allowed them to work through their academic challenges and remain in college.

The participants sought a variety of supports and treatment, and have experienced varying degrees of success.<sup>24</sup> Three are currently taking medication, and two of these participants, Lisa and Dani, are also in therapy. Beth utilizes services from the SDS office, and Kristi is currently not receiving formal treatment, although she is considering it. Kristi, following the advice of a professor, did try to seek services from the counseling center at her university, but found the experience frustrating and ultimately futile. Most of them rely on informal supports and their own coping and management strategies. According to Osgood et al. (2005), most young adults without disabilities rely on their family during their transition from adolescence to adulthood, receiving financial and/or emotional support. Research has also found that positive parental support is associated with higher perceptions of academic competences and higher scholastic achievement (Cutrona, Cole, Colangelo, Assouline, & Russell, 1994; Osgood et al., 2005). However, this support is often limited or unavailable to young adults with EBD, due to strained relationships with their families, or the family's inability, or unwillingness, to assist them during their transition experience (Osgood et al., 2005). In contrast, the participants in the study do have familial support, both financially and emotionally, as previously discussed. Although some of the relationships are sometimes strained, they all remain in contact with their parents and most discuss their issues and feelings of anxiety or depression with at least one, if not both parents. They all expressed a belief that parents and other family members love them and want them to achieve success, and are an integral part of their support system.

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<sup>24</sup> Their experiences with treatment will be discussed in more detail later in the chapter.

When considering receiving treatment and support, both formal and informal, it is necessary to consider the issue of disclosure. The participants found it difficult to talk about their EBD to some friends, family members, and authority figures, such as professors. Tara has not shared her diagnosis with her father or one of her best friends. She is concerned that it might affect the relationships, or that they may not understand. It is important to note that Tara has been recently diagnosed with GAD, and has been taking medication for about six months. Because of the newness of the diagnosis, she may still be processing it, and incorporating it into her identity. Therefore, she may not be ready to disclose her EBD with certain people. Kristi and Dani regret disclosing their EBD with some friends and family members because they believe it has changed the dynamic of their relationships, and that they often feel dismissed because of their EBD. Most of the participants expressed a concern that some people would not understand. However, as previously discussed, most of the participants have found people they trusted, and have developed a network of support, which is a key element to their success and ability to work toward their goals.

Most of the participants are reluctant to disclose their EBD to their professors because they are concerned that they will be perceived as weak or as making excuses. Two of the participants, Lisa and Dani, are at an institution for high achieving students and one, Tara, is in the Honors College of her university. They may be hesitant to disclose their diagnosis because they have always been successful and have taken pride in their ability to excel academically. Asking for extra time or accommodations may make them feel as if they are not living up to their own standards. However, some of the

participants have disclosed their diagnosis. Because Beth is receiving accommodations from the Office of Student Disability Services, her professors are notified each semester. She does discuss her GAD with some of her instructors, particularly if she has to leave the room frequently. Kristi has also disclosed her disability to professors because she felt she had “no other choice.” Dani disclosed to her professors one semester because she was not on medication and was concerned she would not be able to pass the semester. All three met with positive responses when they have talked to their professors, although only Beth said the positive reactions lessened her anxiety about disclosure to authority figures.

Clearly, transitioning from adolescence to adulthood is a complex and challenging experience, particularly for individuals with an EBD. Although the participants must continually manage their anxiety or mood swings, they have found formal and informal supports that have assisted during transition experience. However, much of their success can be attributed to their own efforts and character traits. Each of them displayed self-determination and resilience, important factors that influence transition. Furthermore, the participants reported they did not feel stigmatized or did not feel that stigma played a large role in their lives.

#### Factors Influencing Successful Transition

Barriers that impact educational experiences of students with EBD include stereotypes and stigma, access to information and services, the complex nature of EBD, access to resources, and organization and institutional barriers (Blacklock et al., 2003; Sharpe et al., 2004). However, the participants have been able to “overcome” these

barriers because of their ability to seek support, develop positive relationships and because of their own personal strengths. Although the participants were self-critical at times, they all recognized their persistence and determination. They also remained focused on their goals, even when they faced challenges and obstacles due to having an EBD. During transition, the rapid decline in institutional structure and familial support (Hurrelmann, 1990; Schulenberg & Zarrett, 2006) requires emerging adults to rely on their own sense of agency and resources (Kroger, 2007, p.4). The participants were able to depend on themselves and develop strategies and skills necessary for successful transition. In the words of Beth, they were able to “find ways to manage;” their strengths and ability to adapt enabled them to be successful. Other important factors that influence transition from adolescence to adulthood include self-determination, resilience and stigma. Positive factors such as self-determination and resilience are evident in the participants’ narratives. Further, none of the participants felt they were stigmatized, or that stigma, a negative influence on transition, impacted their experience.

#### *Self-Determination*

According to Wehmeyer (1992), self-determination is comprised of “the attitudes and abilities required to act as the primary causal agent in one’s life and to make choices regarding one’s actions free from undue external influence or interference” (p. 305). Individuals who are self-determined identify goals and the requisites for achieving those goals, participate in career planning and decision making, and advocate for their desires and needs. When asked why they have been able to attend college and achieve success, each of the participants discussed their determination to reach their goals. They describe

themselves as “focused” and knew what they wanted. Beth said that she could have given up on her dream of working in the medical field (either as a doctor or a physician’s assistant) but speculated jokingly, “What else am I good at? I guess I could be a party planner.” The participants’ goal orientation was evident, and they described why and how they arrived at their given career path. When asked how they decided their postsecondary goals, most of the participants responded that it was never a question that they would go to college. Their parents have not only encouraged their college enrollment, but also serve as role models. Both of Lisa’s parents have doctorate degrees and the other participants have at least one parent with a bachelors degree or higher. However, they all chose their majors based on their interests. With the exception of Lisa, all knew they wanted to pursue a career in which they can help others because of their own challenges. Lisa chose philosophy because it was “probably the most challenging major.”

They were also allowed the opportunity to choose their goals and change them when needed. Although Kristi knew she wanted to work with kids, she changed her major to special education on the day of orientation. Although it was an “impulsive” decision, she felt it was the right one and has recently accepted a teaching job working with students with autism at a local school. Tara changed major to audiology from pre-med with support and encouragement from her mother. All of the participants said they felt encouragement from their families to pursue their academic goals but felt they had freedom to choose their majors and career paths. Also, they felt freedom to attend postsecondary institutions of their choice. In fact, Dani had applied and been accepted early, before her parents asked her about what college or university she wanted to attend.

Although Beth's parents wanted her to attend a university closer to home, she moved because she felt it was the best decision for her. Kristi thought about moving away to attend college, but decided staying near home would be easier. Although Lisa had many postsecondary choices in South Carolina, she felt the college she is attending was the right one for her and she was allowed the opportunity to attend school in Florida. In their discussions of how they chose their academic and career paths, it was evident that although they consulted with family members, they were active participants in the planning process, and made the decisions regarding their futures.

### *Resilience*

The participants' narratives also reveal their resiliency, or ability to adapt positively despite adversity. There are multiple factors that are related to resilience, such as a close and supportive relationship with one parent or adult outside the family, positive characteristics of the family and community, pro-social friends, safe neighborhoods, and effective schools (Masten, 1994; Masten, Best, & Garmezy, 1990). Furthermore, sources of protective factors that promote resilience include personality traits and skills, involvements in community groups, churches or clubs, and positive relationships (Masten et al., 2006). The participants demonstrated the majority of these protective factors. They each had supportive relationship with at least one parent, if not both, at least one family member. Although they do not always get along with their parents, they all believe they can turn to at least one, if not both, parents for advice and emotional support. Lisa, Tara and Dani also rely on their parents for some financial support as well. As previously discussed, the participants have developed positive relationships with friends and



boyfriends, and depend on their network of support. All of the participants were able to identify at least one person (and in many cases more) they could turn to who they felt “understood” and could turn to in a time of crisis. Tara described her mother as her “number one” source of strength and she, along with Kristi, Lisa and Dani, rely on their boyfriends, as well as other friends, for support. Although Beth does not like to share her bouts of panic attacks or anxiety with her family and friends, because she does not want to worry them, she has developed a close relationship with the director of the office of student disability services. She also believes she can turn to her family members, particularly her sister, if she needs to.

Most of the participants are also involved in community groups. Tara participates in a university club called Active Minds, an outreach group for students with emotional or behavioral difficulties. Beth attends church and is planning on going on several mission trips this summer. She is also an active member of the student senate. Dani works with girl scouts who are “at risk,” because she feels she can understand what its like to have challenges. Before Kristi graduated college, she was a co-leader for the Best Buddies program, in which members of the program spent time with children with special needs.

Many of these activities demonstrate a desire to help other people. In fact, throughout the narratives, the participants’ desire to care for others and not let other people down appeared to a source of motivation and strength. Most of the participants discussed how they did not want to disappoint their friends and family, and had high expectations of themselves. Furthermore, all of the participants, except Lisa, are entering

careers where they can “help people.” In fact, when asked why they chose their particular goals, Kristi, Tara, Beth, and Dani discussed the importance of helping other people. They all felt like they have survived difficulties and challenges and have something they can “give back” to others. Kristi is starting her first job as a teacher this Fall and Dani plans on entering the Teach America program after graduation. Tara is majoring in Communication Sciences and plans to be an audiologist, and Beth is also entering the medical field. Indeed, Beth says she is happiest when she is working at the hospital, and “actually doing something.”

Another important protective factor that promotes resilience is the individual’s strengths and personality traits. The participants share many characteristics that have enabled them to work towards their goals and achieve success. They are all intelligent, determined, goal oriented, have a desire to help others, have high expectations for themselves, and they have a sense of humor. Also, they have developed coping and management strategies to help them manage their daily stressors and challenges. They all described themselves as persistent and even stubborn, and asserted they “refused” to give up and not reach their goals. Also, they set expectations for themselves and believe they will reach their goals. As previously stated, Lisa and Dani attend a college for high achieving students, and Tara is in the Honors college at the university she attends. Both Kristi and Beth pride themselves on achieving academic success; they all described themselves as smart or intelligent. Further, their belief in themselves and ability to achieve their goals is a salient, and recurring, theme in their narratives. Another significant quality they share is their sense of humor and ability to laugh at themselves.

When sharing what they felt might be embarrassing or “ridiculous,” stories, the participants often laughed, and said things like “what can you do?” or “can you believe I did that?” They were able to find humor in difficult, sometimes painful, events and even laugh at the reactions of other people. Beth summarizes this well, “you have to laugh...or else you would just give up.” The narratives were punctuated with laughter, and most of the participants demonstrated self-acceptance, and even an appreciation of their accomplishments. Another significant trait the participants shared is the ability to cope and manage their EBD. Currently, three participants take medication and two are in therapy. However, they all described ways they manage episodes of anxiety, panic attacks, depression or mania. When asked how they learned these strategies, many of the participants said they picked them up from “somewhere,” or figured out what worked. The participants use a variety of coping strategies, such as exercising, talking to friends, cooking, and breathing exercises. The participants’ desire to help others may also factor into their resilience. This desire is related to many of their goals, such as becoming a teacher or work in the medical profession. Also, many of the participants feel they would let their parents or close friends down if they do not succeed. Finally, the participants displayed a strength of character and resolve; it appeared that having an emotional or behavioral difficulty was a challenge, but a challenge that would not prevent them from reaching their goals.

### *Stigma*

Whereas self-determination and resilience can positively affect transition, stigma can be a negative factor. Stigma is a construct that equates difference, such as an EBD, to

deviance, and often reduces choices and inhibits disclosure. Stigma is a pervasive concept in the literature regarding individuals with emotional or behavioral difficulties, and many researchers have documented that educational opportunities have been often been denied to individuals with EBD because of negative attitudes and beliefs regarding their disability (Unger, 1994; Weiner, 1999). Research has also demonstrated that stigma complicates the transition process because it may reduce choices in fundamental life domains (Osgood et al., 2005, p. 216).

Furthermore, two-thirds of all individuals with EBD do not seek treatment due to the stigma associated with mental health problems (Bush, 2002; Mechanic, 2002; World Health Organization, 2002). Weiner (1999) reports that college students often did not want to disclose their illness because of fear of being labeled or negatively perceived. Many of the participants were reluctant to share their diagnosis with professors because they did not want to be seen as making excuses. It was important for them to be viewed as competent and like “any other student.” However, seeking and obtaining services is often integral to educational and vocational success. Conversely, failure to seek treatment or assistance may lead to poor educational outcomes. Although the participants were uncomfortable disclosing their EBD, they did seek assistance when necessary. Beth went to the Office of Student Disability Services and talks to her professors individually on an “as needed” basis. Lisa and Dani also sought services on their campus, although Lisa has not disclosed her diagnosis with her professors. However, she says she would if she “had to.” Though the participants were sometimes reluctant to disclose their EBD, they did not

believe that stigma was an issue in their lives and did seek treatment when they felt it was necessary.

As previously discussed, stigma is a major risk factor for many individuals with an EBD, and often prevents people from disclosing their diagnosis or seeking assistance. In fact, the National Alliance on Mental Illness (NAMI) recently began a “stigma busters” campaign to counteract negative stereotypes, encouraging individuals to report demeaning images, language, and advertisements at the local, state and national level. (NAMI, 2008). The participants’ ability to not define themselves as stigmatized, or deviant, but rather to accept their EBD as part of their lives, as challenging as it can be, may be another contributing factor to their success.

#### Implications

Educators, mental health service providers and higher education faculty need to be aware of the unique needs and challenges of emerging adults with emotional and behavioral difficulties. Sometimes, medications do not work, or individuals may be resistant to therapy. Also, some therapies may not address the particular needs of a given client. A diagnosis and a treatment plan, while important to recovery, are not sufficient for emerging adults with an EBD. Students, parents and teachers need guidance regarding issues surrounding medication (e.g., side effects, reluctance to taking medication), the need for continuing coping and management strategies, and how to plan for additional stressors and challenges that will occur during the transition process. Also, teachers and mental health service providers need to be sensitive regarding ethical issues such as privacy and disclosure.

### *Implications for Teacher Education and Practice*

Although the participants in this study have protective factors, such as familial supports, high academic achievement, parents with bachelors or advanced degrees, that many students may not possess, the participants' narratives reveal implications for teacher education and practice. For example, students can develop self-determination and goal orientation; they can also be taught how to advocate for themselves and develop management and coping strategies. Future special and general educators need to learn how to prepare students with EBD for transition by empowering them by helping them develop the necessary tools for successful transition. For example, self-determined individuals participate in decision making, identify goals and the requisites for achieving those goals, participate in selecting courses and career planning, and advocate for their desires and needs (Levine & Wagner, 2005; Wehmeyer, 1996). It is also important to note that academic achievement at any postsecondary level, including community college, vocational training and occupational certification can lead to successful careers. Further, career directedness is important factor to successful outcomes, even when career paths change.

Students with EBDs should be exposed to a variety of career options; they should visit postsecondary institutions, attend job fairs, and learn about different opportunities. They should also explore what types of careers or jobs that interest them or suit their abilities. Many students in segregated classrooms or schools do not participate in these types of activities; therefore, they may believe their options are limited. Students should also be encouraged to set goals and determine how they can achieve them. In many cases,

many students believe they do not have control over their futures, or feel their opportunities are restricted. They may also lack role models who attended postsecondary institutions or pursued their career goals. The participants in the study have at least one parent who has earned a college degree. Both of Lisa's parents have doctorate degrees and are scientists. Most of the participants have also had opportunities to work in a variety of settings, which helped them determine their career goals. For example, Beth started working in a hospital when she was in high school where she was encouraged to pursue a career in medicine. Kristi worked with students with special needs when she was in high school and college and has recently obtained a job as a career counselor. Dani also worked with children as a camp counselor and plans to work in the Teach America program.

It is also important for future educators to learn how to teach students to be self-advocates. All of the participants were able to recognize they needed support and sought assistance, even if they felt uncomfortable. Tara went to the doctor by herself as soon as she turned 18 because she knew she could not "keep things the way they were." Beth sought assistance for test anxiety when she began struggling during her courses and elected to take additional courses on study and test taking skills. In fact, she attributes a lot of her success to the methods she learned in these courses, rather than formal treatment such as therapy or medication. Lisa, Dani and Kristi also sought treatment on their own, despite resistance from their parents. Students with emotional or behavioral difficulties need to learn how to ask for assistance, in an appropriate and productive manner. The issue of disclosure is pertinent here. Many young people do not know how,

when or who to disclose to, and often confide in people they should not trust. For example, when Dani was diagnosed as having depression when she was in middle school, she shared with a few friends who gossiped about her and spread rumors. Also, students may wait until after they are “in trouble” and they may not be taken seriously, and that they are merely offering excuses. This is a delicate issue because it is important for young adults to understand they should not disclose to everyone, but educators and other professionals do not want to make the students feel stigmatized.

Teachers can also help students with EBD develop coping strategies, such as monitoring moods, taking breaks when they feel anxious or stressed, exercising, or asking for help from trustworthy and reliable individuals. All of the participants have developed successful coping and management strategies but many are unable to identify where they learned these techniques. Beth said she “picked up” some of the ideas from the study skills course she took but developed others on her own. Lisa learned how to interrupt negative or critical thoughts during therapy and utilizes a lot of strategies she has learned in therapy. The other three participants, however, have developed their coping strategies through “trial and error” and figuring out what “works.” Many students with an EBD may not have this capacity and need more guidance and support to develop coping strategies.

#### *Implications for Mental Health Service Providers*

Many clinical and ethical issues emerged during the participants’ narrative of their experiences. All of the participants discussed the issue of medication at length. Most of them discussed the many types of prescription drugs they were given and their



frustration with the experience. Lisa became “disheartened” when the psychiatrist told her he had “nothing left to give her” after she tried many types of medication. While she takes two psychotropic drugs, she uses marijuana on a daily basis because it is the only thing that gives her a break from her “constant narrative.” Although they both continue to struggle with anxiety and panic attacks and wish were excited about the prospect of taking medication when they were diagnosed initially, Beth and Kristi decided not to take medication because “nothing worked” and they experienced negative side effects. The participants, with the exception of Tara, felt that their psychiatrists were just “trying things out.” Although psychopharmacology is not an exact science, perhaps more research and improvement of psychotropic medication would improve outcomes and encourage individuals to continue medication, if needed. This raises another issue. All of the participants were placed on medication immediately, before the therapists or psychiatrists tried alternate means of treatment, such as cognitive behavioral therapy or other evidence based practices. As previously stated, Beth has found the testing accommodations and information she learned at a study skills workshop more helpful than any of the formal treatment she received. Many of the participants are uncertain they want to take medication “for the rest of their life” and may benefit from other forms of treatment.

Another important aspect regarding medication is that many individuals stop taking their prescribed drugs without the knowledge of their doctors and therapists. Kristi did not tell her doctor she discontinued taking Paxil until two weeks later, and experienced a “crash,” which led to depression and an “inability to do anything.” Lisa

decided to stop taking Remeron and Klonopin for a year, and began to use marijuana “all the time” and describes that period as “awful.” Dani is still ambivalent regarding the use of medication because of the way it affects her moods and makes her question her identity. She recognizes the need for it, but says she is not 100% sure she wants to be on it for the rest of her life. There are individuals with EBDs, such as schizophrenia or bipolar disorder that do need to continue medication. Perhaps more awareness and education regarding the importance of continuing treatment is needed.

Several ethical issues were raised during the participants’ narratives. Beth’s files and chart were given to a psychiatrist without her knowledge. She went to the counseling center seeking assistance for her test anxiety, and was told she needed to come back later to talk to someone else. The in-take counselor did indicate she had concerns but did not tell Beth she was referring her to a psychiatrist, and Beth was “shocked” when she realized who she was seeing and that he had her chart. Kristi felt that her first therapist crossed several boundary issues and made her therapy “all about her mom.” At first, Kristi did not know that the therapist was treating both her and her mother and it became very “complicated.” Also, Kristi believed, and rightly so, that the therapy sessions should have addressed Kristi’s needs and that she should have known that her therapist was also treating her mother. Trust is an integral part of therapy, as is respecting boundaries, Kristi believed this therapist violated both of these elements and was reluctant to seek other treatment. When she did see another therapist, he was also treating her mother but was upfront about it. Kristi and her mother had the same insurance company, and their provider options were limited. She says she will now consider returning to therapy

because her mother no longer lives in the same state and she will not have to worry about that issue. Dani also experienced a situation that raises ethical questions. She was originally diagnosed with depression but one doctor placed her on Depakote without her knowledge, and did not tell her or her parents that she may have bipolar disorder. She only learned this information when her current psychiatrist diagnosed her with bipolar disorder. Dani's parents allowed her to stop taking medication when she was an early teen because they believed her depression was situational and that she no longer needed to take it. If they had been better informed, they may have made a different decision, which may have allowed Dani to have a smoother transition from high school to college.

Unfortunately, only a small percentage of 18- to 25-year-olds receive mental health treatment or services (Vander Stoep et al., 2000) and many are under-identified, particularly girls. Although the participants' treatment and services were not always successful, they have found supports that are useful. Furthermore, most of the participants were experiencing difficulties in high school but managed to "stay under the radar." Female students are often not identified with having an EBD because they often internalize their feelings. All of the participants expressed a need to be independent and not be seen as weak or needy; therefore, they did not want to ask for help or seek assistance. Dani's and Tara's parents did send their daughters to a psychiatrist after discovering troubling signs (Dani's letter, evidence of Tara's cutting), but they stopped treatment either before or during high school. Although they felt anxious or depressed, they did not seek treatment until they turned 18. All of the participants suggested the need for confidential counseling in high school and middle school, believing that it would be

helpful for students to have a “safe” outlet and place to discuss their anxieties and feelings. Many of them said they would have utilized these services, and believe that many of their friends or classmates would have benefited from them.

Although the participants faced challenges regarding treatment, they were able to continue to seek the help they needed, or develop strategies that are useful to them. Not all students have the same resilience or strength of character to remain persistent and advocate for their needs. Many emerging adults who do receive mental health services encounter a fragmented and complex system, including both private and public service sectors (Gralinski-Bakker, Hauser, Billings, & Allen, 2005). Furthermore, many students lack the ability to advocate for themselves or the determination to continue to seek the supports they need. Also, negative experiences may discourage individuals with EBDs from continuing treatment which may be integral to their success.

#### *Implications for Higher Education*

Several implications for higher education were manifest throughout the participants’ description of their experience. Although some participants disclosed their EBD to their professors, all were reluctant to discuss it with their instructors. Furthermore, most did not seek help from the Office of Student Disability Services, and sought other avenues of assistance, such as private doctors or counseling services.

The participants may have been reluctant to share their EBD with their professors because they did not feel comfortable disclosing this information. They were afraid of being viewed as “weak” or “making excuses.” They may have been more willing to disclose this information if professors explicitly and verbally expressed a willingness for

students to ask for assistance if they have an EBD. Perhaps faculty members are hesitant to encourage disclosure because they do not feel equipped to deal with issues related to emotional or behavioral difficulties. More training and information regarding working with students with EBD may be beneficial to faculty and may promote a more open dialogue between professors and students.

Furthermore, students were reluctant to seek services from the SDS office. Only Beth is currently receiving accommodations, and has found them “extremely helpful.” In fact, she has developed a close bond with the director. However, she noted that while her professors are notified, they are given limited information, and she needs to explain her EBD in more detail. Perhaps providing professors with more specific information could benefit students.

It is also important to note that Beth attends the satellite campus, which is much smaller than the main campus. Kristi, who attends the main campus of a large university, attempted to seek assistance from the Office of Student Disability Services, but found the experience frustrating. In fact, she believes that the process needs to be “less intimidating and stressful.” When she did “force” herself to “walk through those doors,” she was sent away because she did not have the correct paperwork. She also believes that “a lot” of people need help but do not seek services because the process is so “difficult and overwhelming.” Currently, the responsibility to seek accommodations relies solely on the students. When students with EBD do need assistance they may be in crisis and not able to handle a long and complicated process. Furthermore, students may not know the services available to them. Tara did not know “how they could help,” and Kristi asked,

“even if I did go, then what?” Kristi suggested making the process easier, perhaps having faculty members work with the Office of Student Disability Services to assist in the process.

The numbers of students with EBD attending college is increasing rapidly, and institutions of higher education need to respond to the unique needs of these students. Providing faculty and staff with information on how to work with these individuals may lead to greater success for this population. Furthermore, educating students on the availability of services, and making the process of receiving assistance easier, may encourage students to seek help, which may also lead to student success.

#### Contributions to the Literature

The majority of research revolving around young adults with emotional or difficulties examines the largely negative outcomes regarding this population (Jolivet et al., 2000; Wagner, Cadwaller, Newman, & Marder, 2003). Even though the number of transition-aged individuals with EBD is significant, few studies have explored the experiences of this population engaged in educational activities. This study hoped to illuminate factors that contribute to successful transition for selected emerging adults. Most studies regarding individuals with emotional or behavioral studies are quantitative or use case study or grounded theory methodology; few use phenomenological research methods. In order to gain a better understanding of the contribution of this study, both the participants’ and researcher’s reflections are discussed.

### *Participant Reflections*

When asked to share their reflections regarding their experience participating in the study and their thoughts on the study, the participants discussed the topic of the study and how participating in this research has benefitted them. During the follow up interviews, many participants stated that the interview was the first time they really talked about their “entire” history of their EBD and how it has affected them, but found it beneficial to examine their experiences. Many of the participants stated that it helped them recognize the progress that they have made and “how far they have come.” So although these questions caused the participants to perhaps think about the impact of their EBD in a different way, most appeared to benefit from the experience. For example, Kristi was:

*Extremely* nervous about the interview because I don’t like to talk about this...but it was good, and I was really proud of myself afterwards because I thought I would be upset, but it showed that I have grown in terms with who I am and how I cope... (I could) talk to somebody and not tear my life apart...I was so excited, I call (her boyfriend) afterward and said “I did it, I did it, I’m okay!” So it was definitely a good experience.

Lisa used the experience to organize her thoughts and talk to her parents about why she is in treatment:

Talking with you helped me organize how I think about it (her GAD) so I tried to explain it to them better. That’s when my mom said she experienced the same thing, that same nagging narrative, and thought it was her father’s voice.

Lisa talked to both her parents and felt that not only did it provide them a better understanding of what she is going through, she gained insight into her parents as well. “It (talking about the interview and her answers) really opened up a conversation.”

Most of the participants shared that they appreciated the “positive” focus of the study, and were “happy” that someone wanted to hear about their successes, rather than just what “was wrong” with them. According to Tara:

It’s (living with an EBD) really hard to deal with this, especially when you hear negative things, because it is easy to beat yourself up and it could easily become a crutch, oh well, nobody can succeed, so it’s okay, and that’s not true. It’s a very small part of who I am, so it is nice to find people who are interested in my successes because I’ve worked extremely hard to get where I am, so it is kind of refreshing (with laughter).

The participants also appreciated the “positive” focus of the research because it allowed them to be a part of something that may help others:

I (Kristi) like to be a part of things that could help people. I know that it is important for people to research these things, and I feel good being able to contribute and so I was excited to be able to be a part of something, and it not be in a negative sense. I don’t want to get with a group of people that have disorders and sit and talk about it and more, but to be able to talk to somebody and tell them what it is like, it is exciting for me, and it is helping people be aware.

Beth believes that sharing her story can be beneficial to others:



I always take things on myself, but I am more with it, so if I can help other people, that would be great. That is why I was very happy to do this with you. So that's my little step of doing it. At the community level...when (the director of SDS) told me about this, I was like "I'll do it. Why not?" I thought it was cool that someone wanted to hear my story...and I'll tell it to whoever wants to hear it (with laughter).

Lisa discussed the importance of the topic, both for her and other students:

I'm really glad your topic was what it was because the transition between HS and college was such a crisis for me and my life so it is one of the most important things, but I don't talk about it to many people. It is a really important subject to be looking at, we do have so many kids going to college, more than anywhere else, but there's certain responsibilities people aren't prepared for, I was lucky because I had college professor parents and I was always in that atmosphere.

There are drawbacks to that, but at least I knew what was expected of me, which I don't think many people have, or know when you leave high school, how prepared you are supposed to be.

Although many of the participants cried or appeared upset during the interview, none of them stated they regretted the experience and believed they benefited from it in some way. In fact, two of the participants were reluctant to take the stipend because they did not feel it was "necessary" and "would have done it without it (financial incentive). It was evident the participants appreciated an opportunity to share their stories and successes.

### *Researcher Reflections*

According to Nietzsche (2000), whose philosophy helped shape phenomenology and phenomenological research methods:

Every word instantly becomes a concept precisely insofar as it is not supposed to serve as a reminder of the unique and entirely individual original experience to which it owes its origin; but rather, a word becomes a concept insofar as it simultaneously has to fit countless more or less similar cases — which means, purely and simply, cases which are never equal and thus altogether unequal.

Every concept arises from the equation of unequal things. Just as it is certain that one leaf is never totally the same as another, so it is certain that the concept "leaf" is formed by arbitrarily discarding these individual differences and by forgetting the distinguishing aspects. p. 55

If we consider the transition experience to adolescence of adulthood of emerging adults with an EBD as a concept, Nietzsche's words are applicable to this study. The experience for each participant is a unique case and not equal to other cases, although most research studies, particularly ones that examine outcomes or attempt to derive theories, conflate these experiences to a concept, or construct, discarding the "individual differences" and "forgetting the distinguishing aspects" of each experience. Phenomenological research, while interested in the commonalities of an experience, also provides an opportunity for individuals to share their stories and illuminate the distinct aspects of their experiences. This type of research may obtain valuable information and insight by examining the individual's experience as a unique and worthy subject.

Therefore, the individual stories of emerging adults with an EBD are significant. The phenomenological process begins with a conscious self, who imagines, perceives, thinks, remembers, and judges (Ihde, 1979). The researcher selected phenomenological research methods in an attempt to study and illuminate the distinct experiences and individual perspectives and insights not otherwise acquired through other research methods. Although there are many commonalities, or intersections, of the participants' stories, each participant does have her own story to tell. It is important to hear and attempt to understand the individual "words" and to give voice of the participants, rather than only examining the concept of transition for emerging adults as a unified whole. However, the participants do share a common language, particularly regarding therapy, medication and their diagnoses and similar experiences, such as negotiating disclosure and developing coping strategies. It is important to note that what they have in common is created knowledge, developed by scientists, social scientists, and cultural constructions (Foucault, 1970). It is essential to examine and understand these intersections and commonalities, which can inform how we work with adolescents and adults with emotional and behavioral difficulties.

One of the most surprising aspects of this study, and perhaps one of the reasons this research method is valuable, is the willingness of the participants to share their stories. Each participant answered, and even elaborated on, questions and disclosed personal and sometimes painful information. This may be due to the focus of the study and the researcher's interest in their strengths and achievements. Also, phenomenological research honors the voice and experiences of the individual, rather than attempting to

draw conclusions or form judgments. The participants responded positively to this approach and provided valuable insights regarding their transition experience. Furthermore, the participants appeared to benefit from their involvement in this research. As previously discussed, they were able to reflect on their journeys and appreciate their own progress. They also appreciated the opportunity to share their experiences and their personal achievements.

### Implications for Future Research

Because there are limited studies exploring the experiences of emerging adulthood with emotional and behavioral difficulties, there are many implications for future research, and many different directions in which this topic can be explored. For example, this study could be replicated exploring the experiences of different populations, such as male college students, or individuals who are enrolled in vocational programs or engaged in full time employment. Studying the experiences of these groups may provide additional information and insights. Examining the experiences of a variety of individuals could lead to a development of a service model to assist young adults transitioning from high-school to postsecondary life. Including the experiences of students receiving special education services or are considered at risk would be vital to developing such a model. Another study could also explore the experiences of individuals who have provided support for emerging adults with emotional or behavioral difficulties. As the findings of this study indicated, positive and supportive relationships are key factors to success.

There is also merit in pursuing the transition experiences of female emerging adults. It would be interesting to continue this research studying the same population to explore if there are commonalities due to gender. For example, most of the participants were reluctant to seek assistance until it was “absolutely necessary,” and many still do not disclose to authority figures. As previously discussed, girls with emotional and behavioral disorders are under-identified and may have a desire to stay hidden or not be perceived as weak or incompetent. Another possible commonality is the desire to help others and not disappoint friends and family members.

George Kelly’s (1955), who developed the psychology of personal constructs, observed that, “Man looks at his world through transparent templates which he creates and then attempts to fit over the realities of which the world is composed.” (pp.8-9) Understanding the kinds of constructs that give meaning to the lives of emerging adults with emotional or behavioral difficulties, such as personal inadequacy or feelings of rejection, and what kinds of compensatory constructs are required (e.g., self-reliance, determination) may provide useful information for improving transition outcomes for young adults with an EBD.

#### Ethical Considerations

As a researcher, this study has provided an opportunity to enter and, to a small extent, participate in the life space of five young women with an EBD. The interviews were relaxed and in many respects conversational. The ethical challenges of hearing their stories without invading their privacy, however unwittingly, by encouraging them to share more than they intended, were always present. The ethical dilemma of gaining their

trust while not crossing the line to elicit information they might later be sorry they shared was a frequent issue of judgment on the researcher's part. Learning true and meaningful stories needed for the study while protecting the participants' privacy and supporting their will to withhold information that was too personal required a balancing act between the needs of the study and the rights of the participants. The researcher's ethical and professional's responsibility was to maintain a structure that did justice to the study and not confuse that role with therapy.

### Conclusions

The concept of 'emerging adults' signals one of the challenging and complex intersections of human development. This intersection is filled with biological, social and psychological variables, the interaction of which is amplified by emotional and behavioral difficulties. Research on EBD is focused primarily on children, and the existing research on emerging adults is focused on outcomes and treatments. This is the result of prioritizing interest in research inventions and quantitative research methods.

The present study focused on the lives of selected emerging adults and the ways they experience their emotional difficulties, and the ways their EBD is manifested, creating challenges not experienced by typically emerging adults. This study has prioritized understanding individual experiences and giving a voice to young women with an EBD. In order to accomplish this, the researcher utilized a phenomenological research design. In the researcher's experience of conducting interviews and analyzing data, it was evident that the participants, recognizing their own existential identity, want to and need to be heard.

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## Appendices



## Research Study Seeking Young Adults with Emotional or Behavioral Difficulties

*This is a special opportunity to give young adults with emotional or behavioral difficulties a voice, and to help researchers understand the experiences of individuals with emotional or behavioral difficulties pursuing their academic and professional goals.*

**Participation involves two to three interviews (approximately one hour each) in your home or agreed upon location.**

Please contact Kati Fowler for further information:  
[kfowler@tempest.coedu.usf.edu](mailto:kfowler@tempest.coedu.usf.edu)  
941-538-0234

*You are eligible to participate if you:*

*Are between the ages 18 and 25*

*Have been identified as having an emotional or behavioral difficulty, such as, but not limited to, bipolar disorder, depression, anxiety, schizophrenia, or adjustment disorders*

*Are enrolled in postsecondary academic institution*

*Participants will be given a \$50 stipend as a token of appreciation.*

*Participants' confidentiality will be respected and ensured.*

## Appendix B

### Personal Statement: Role of the Researcher

As suggested by Moustakas (1994), I have chosen a topic that has both “social meaning and personal significance” (p. 104). Accordingly, it is necessary for me to examine my own beliefs, experiences, and assumptions regarding the transition experiences of individuals with an emotional or behavioral disorder. Throughout the research process, I have maintained a reflexive journal in order to clarify my thoughts and values, and to remain aware of how my beliefs may color the focus of the research, data collection and analysis, and reflections of the phenomenon being studied.

#### *Developing the Topic and Research Questions*

The decision to examine the experiences of individuals with emotional and behavioral disorders stems from my professional experiences. I taught students with an EBD for six years, and observed how many students struggled to graduate high school, and upon graduation, had even more difficulty successfully transitioning into adulthood. However, I noticed that some students were able to pursue academic goal and/or obtain gainful employment and become functioning members of society. Also, as a college instructor, I have worked with many students who have an EBD and who have, or are working on, reaching their academic goals. Because of these experiences, I believe that individuals with emotional or behavioral disorders can successfully transition into adulthood. Therefore, my study focuses on positive outcomes of individuals with EBD,

rather than the predominant negative outcomes of this population. As I developed my research questions and interview protocol, I needed to be aware of this focus and not exclude questions that examine the difficulties and challenges of having an emotional and behavioral difficulty. I also believe that there are not adequate supports for individuals with EBD; therefore, in addition to asking what other types of assistance are needed, I included questions about supports and services that have helped students as they transition from adolescence to adulthood.

### *Data Collection*

The data collection process was fraught with challenges regarding my role as a researcher. Because this is a phenomenological research study, I interviewed participants using a semi-structured protocol. This method of data collection involves careful listening and attention to the participant. I had to hear what the participant was saying, rather than be distracted by my own assumptions and feelings, particularly when I asked probing questions that were not included in the interview protocol. Also, because of my personal and professional knowledge regarding emotional and behavioral disorders, it was sometimes difficult not to evaluate the participants' responses regarding their diagnoses and treatment. It was particularly difficult, if not impossible, to refrain from offering encouraging responses, support or advice.

Throughout the data collection process, I had to remain vigilant as a listener, and not ask leading questions, or attempt to prompt certain responses. For example, although I believe stigma is a challenge to the transition process, some participants did not mention stigma or negative perceptions regarding their disability. When asked if they ever

disclosed their disability and regretted it, I was often surprised to hear participants respond that they had not. Although I did ask participants to expand on their answer if they simply said no, I was careful not to prompt a different response by pursuing the topic further. Conversely, there were times when I needed to ask additional questions. As stated previously, I assume that individuals with an EBD can be successful; however, I cannot assume that all participants in the study are feeling or experiencing success currently, despite attending a postsecondary academic institution. Therefore, it was necessary to listen carefully as participants described their challenges, and ask follow up questions that were not included in the original protocol.

I also assume that individuals feel, and are aware of, difficulties due to having an EBD. When asking certain questions, such as “how has having an EBD affected your relationships” or “how has it affected your academic goals,” or “what challenges you,” several participants needed a long time to respond, some initial statements included “I never really thought about that,” or “good question...let me think.” During the follow up interviews, many participants stated that the interview was the first time they really talked about their “entire” history of their EBD and how it has affected them, but found it beneficial to examine their experiences.

According to Moustakas (1994), one of the problems researchers face when conducting a phenomenological study is knowing too much about the topic. During the interviews, I wanted to make comments regarding their diagnosis or medication based on their descriptions of their symptoms and behaviors. For example, one participant has recently been diagnosed with bipolar disorder, and her description appeared to match this



diagnosis. However, she then questioned whether she was bipolar or not, saying “I’ve read a lot of the research, and I don’t think I am that extreme,” or “I don’t spend money I don’t have.” I found myself wanting to tell her that I thought the diagnosis was correct, but asked follow up questions, such as have you discussed this with your psychiatrist?” During several of the interviews, I became very interested in the diagnoses and different types of medications and treatments. When I realized I was asking numerous follow up questions, I had to remind myself of the focus of the study, and that the purpose was not to diagnose the participants.

One of the most difficult aspects of the data collection process was not being able to offer encouragement, support, or advice. I often wanted to respond to answers with statements such as “I know,” “I understand,” etc. Withholding empathy and compassion was challenging because I value the participants’ willingness to share their experiences and had a desire to offer support or encouragement. I also had to concentrate on not revealing my personal thoughts through non-verbal communication. At times, I became distracted by my efforts to control my facial expressions, and would have to ask the participant to repeat their response so I could ask further questions. The follow up interviews did give me the opportunity to ask additional questions when necessary.

During several of the interviews, I wanted to offer suggestions or advice regarding medication and therapy. For example, the participant with bipolar discussed how she frequently goes on and off her medication, and I wanted to encourage her to stay on her medication. Another participant has had difficulty finding the right medication to treat her anxiety, and I wanted to discuss different options. Again, I had to remind myself

that I was not here to diagnose the participants, and did not pursue the subject. One participant revealed that in addition to taking Klonopin and Remeron, she uses marijuana twice a day. Although I did not comment at that point, I did say “good, I am glad” when she said she told her therapist that she was using marijuana, as I was concerned that she was doing something potentially dangerous.

As a beginning researcher, I am learning how to not only be aware of my assumptions and feelings, but to manage them, as well as my responses, during all aspects of the research process. Recognizing how my beliefs and assumptions influence the development of my topic and questions and data collection has also guided my data analysis and synthesis of my findings.

## Appendix C

### Interview Protocol

#### Opening

“Thank you for volunteering to participate in this research study today. The purpose of this interview is to help me understand the transition experiences that you have gone through as a young adult with an emotional or behavioral difficulty. The results of this study will potentially help other individuals and educators learn how to improve transitional supports for young adults with an emotional or behavioral difficulty and to better understand experiences of this population. You were selected for participation in this study because you are a young adult between the ages of 18 and 25, have been identified as having an emotional or behavioral difficulty, and are currently enrolled in an educational, vocational program, or are employed full time.

The interview will be recorded in order for me to review at a later time, and to ensure that I am capturing what you are sharing in an accurate manner. Please note, there are no right or wrong answers; I am simply hoping to learn more about your experiences transitioning from high school to your current academic or vocational pursuits. Before we begin, let’s set a few ground rules. This interview will last up to 90 minutes. We will really try to respect these time limits. Also, I may say some things that sound repetitive, such as “tell me more about that” or simply repeating back what you said in order to ensure that I am really understanding your experiences. If at anytime you feel uncomfortable, please let me know, and we can move on to the next question or reschedule the interview for a later time. Do you have any questions? If you’re ready, let’s begin.”

#### Questions

“Every individual has a story. Please tell me about your experiences after graduating high school and pursuing your academic or vocational goals, particularly as affected by having an emotional or behavioral difficulty.”

he researcher will use a combination of clarification and paraphrasing in order to ensure accurate understanding of the participant’s story. In addition to asking the primary research question, the researcher will ask the individual an open-ended follow-up question about topics listed below. For each area, the researcher will ask: “Tell me more

about \_\_\_\_\_” or “There are other things I was wondering about. Tell me more about....”

## Topic Domains and Prompts

### 1. Disability

- When were you first diagnosed?
- What events led up to diagnosis?
- What was your reaction to diagnosis?
- How do you feel about your diagnosis now?
- Has this diagnosis changed the way you think about yourself?
- How have the reactions of others and attitudes of other people changed the way you think about yourself?
- How would you describe its affect on your ....
  - Academic or career path
  - Friendships
- Other relationships
- Identity

### 2. Disclosure

- How do you decide when to disclose your psychiatric disability?
- What do you consider before disclosing your diagnosis?
- Have you ever shared with someone and regretted it?
- Ever not shared and regretted it?
- How do people react when you disclose diagnosis?

- Discuss a positive reaction.
- Discuss a negative reaction.
- How do you handle negative reactions?

### 3. Goals

- When did you graduate high school?
- What are you doing now?
- What are your educational plans?
- Career plans?
- How did you decide your current goals?
- Did your disability influence your decisions regarding your academic or career goals?
- How?

### 4. Assistance and support

- Are you currently receiving assistance? What kind? Why did you decide to receive assistance?
- What types of assistance have you received since you were diagnosed?
- Describe how they helped you.
- Describe their impact on your transition into postsecondary or vocational settings.
- What encourages you to seek assistance?
- Do you ever want assistance but do not ask?
- Why? What factors do you consider?

- What types of services are helpful? What other services are needed?
- What is difficult about asking/receiving assistance?
- What additional supports have helped you as you work towards your vocational or academic goals? (familial, community, educational)
- What/who has been the most helpful?

#### 5. Challenges

- What types of obstacles have you encountered while pursuing your goals?
- Give a specific example...
- How did you handle that?
- Did you seek assistance?
- Why or why not?
- What is challenging to you?
- What would you want other people to know about your experience?
- Do you feel you face additional pressures because of your..
- How do you manage those?

While the interview is being recorded, the researcher will listen and take notes highlighting important statements and reflections.

### **Closing**

If an additional in-depth interview is not needed, the researcher will use this script:

“Thank you for participating in this portion of the study. As I had explained previously, I will transcribe the recording from this interview and share examples of your interview transcript when we meet next time. At that point, you will have a chance not only to expand on what you’ve already said, but also to add any additional information about your experiences. Once we finish that task, your role in this study will be completed and I will provide you with the stipend we had discussed previously. Thanks again.”

If a second in-depth interview is needed, the researcher will use this script:

“Thank you for participating in this interview. We will need additional time to complete this portion of the study. When would you be available to meet again? Would you like to meet in the same location? Okay, we will meet at \_\_\_\_\_ (date) at \_\_\_\_\_ (time) at \_\_\_\_\_ (location). Thank you so much for your time.”

After the second in-depth interview is completed, the researcher will use the script from above, repeated here:

“Thank you for participating in this portion of the study. As I had explained previously, I will transcribe the recording from this interview and share examples of your interview transcript when we meet next time. At that point, you will have a chance not only to expand on what you’ve already said, but also to add any additional information about your experiences. Once we finish that task, your role in this study will be completed and I will provide you with the stipend we had discussed previously. Thanks again.”

After the interview(s) is (are) conducted, the researcher will transcribe data and look for common themes within the topics. Following this step, the researcher will utilize the theme verification protocol stated below:

1. Make telephone contact with the participant and set up a meeting for 60 minutes (15 minutes for rapport and purpose, 45 minutes for theme verification).
2. The researcher will introduce up to five selected segments of the participant’s interview transcript and ask the following questions for each segment:

- a. “When I asked about (question), you mentioned (read transcript). Does this sound like what you meant to say?
  - b. Is there a way that I should modify the statement to reflect a more accurate portrayal of your experiences?
  - c. Are you pleased with/do you agree with this segment?
3. After each segment has been reviewed, the researcher will ask participants if there are any other questions, or if there is anything they forgot to mention during the initial interview.
4. Finally, the researcher will ask the participant if she can contact them in the future if she has any questions, provide the \$50 stipend, and thank them for their time.
5. The researcher will provide her phone number and invite participants to contact her if they have questions or concerns regarding the interview(s).



## Appendix D



### **Informed Consent to Participate in Research Information to Consider Before Taking Part in this Research Study**

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Researchers at the University of South Florida (USF) study many topics. To do this, we need the help of people who agree to take part in a research study. This form tells you about this research study.

We are asking you to take part in a research study that is called:  
The Transition Experiences of Selected Emerging Adults with Emotional or Behavioral Difficulties

The person who is in charge of this research study is Kathleen (Kati) Fowler.

The research will take place at a convenient location for you. Options include your home, the University of South Florida, or another agreed upon location

### **Purpose of the study**

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The purpose of this study is to explore the question, “What is the transition experience of selected emerging adults (ages 18-25) with an emotional or behavioral difficulty?” That is, the purpose of the study is to help me understand your experience after you graduated high school and began college. Another purpose of this study is to

identify supports and services that have helped you in your transition from high school to your current college or vocational setting.

### ***Study Procedures***

If you take part in this study, you will be asked to respond to answers regarding your experiences transitioning from high school to your current program or employment. You will need to come for two, possibly three, interviews in all, approximately 1 to 2 weeks a part. At each visit, I will:

- Interview you and ask questions about your experience as a young adult identified with an emotional or behavioral difficulty. You will also be asked about leaving high school and beginning college, a vocational program, or a full-time job.
- The second interview will either explore these questions more in-depth or be used to allow you to read the transcripts of your interview and clarify or make corrections, as needed.
- If additional time is needed, we will schedule a third interview.

The research will take place at a convenient location for you; either at your home, the University of South Florida, or another agreed upon location. Your story will be recorded in order for me to review at a later time to make sure I am capturing what you are sharing in an accurate manner.

### ***Alternatives***

You have the alternative to choose not to participate in this research study.

### ***Benefits***

The potential benefits to you are:

- An opportunity to share your experiences as an individual with an emotional or behavioral difficulty who is working toward their professional and/or academic goals.

### ***Risks or Discomfort***

There following risks may occur:

- Discussing your experiences may bring up painful or uncomfortable emotions or memories.

If you have any of these problems, tell me at your next visit. If these side effects bother or worry you, or if you have other problems, call me (Kati Fowler) at 813-417-8483 or 941-538-0234.

You may also want to go to your regular counselor or therapist. Tell your counselor or therapist that you are taking part in this study. If you can, take a copy of this consent form with you.

If you do not have a counselor, you may call one of the following numbers:

Crisis Center of Tampa Bay, Inc. 813-964-1964

Manatee Glens 24 hour Crisis Hotline 941-741-3117

### **Compensation**

- You will be paid for the time you volunteer while being in this study. As a token of appreciation, you will be given \$50 for the study. You will receive \$25 for the first interview and \$25 total for the second and third interview.

### **Confidentiality**

We must keep your study records confidential. Federal law requires us to keep your study records private. We will use the following procedures to protect your privacy:

- The recording device used to tape your interview will be erased once the information it is transcribed into a word document.
- The transcription stored on the computer or other storage devices will not contain any information that could be used to identify you, such as your name, birth date, contact, etc.
- Data that contains information that could identify you will be stored in a locked cabinet.

However, certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The researcher's dissertation committee.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.) These include:
  - The University of South Florida Institutional Review Board (IRB) and the staff that work for the IRB. Other individuals who work for USF that provide other kinds of oversight may also need to look at your records.

We may publish what we learn from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are.

### ***Voluntary Participation / Withdrawal***

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study, to please the investigator or the research

staff. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

**Questions, concerns, or complaints**

If you have any questions, concerns or complaints about this study, call Kathleen (Kati) Fowler at 813-417-8483.

If you have questions about your rights, general questions, complaints, or issues as a person taking part in this study, call the Division of Research Integrity and Compliance of the University of South Florida at (813) 974-9343.

If you experience an adverse event or unanticipated problem call Kati Fowler at 813-417-8483.

***Consent to Take Part in this Research Study***

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

**I freely give my consent to take part in this study.** I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

\_\_\_\_\_  
Signature of Person Taking Part in Study

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Person Taking Part in Study

***Statement of Person Obtaining Informed Consent***

I have carefully explained to the person taking part in the study what he or she can expect.

I hereby certify that when this person signs this form, to the best of my knowledge, he or she understands:

- What the study is about.
- What procedures/interventions/investigational drugs or devices will be used.
- What the potential benefits might be.
- What the known risks might be.

I also certify that he or she does not have any problems that could make it hard to understand what it means to take part in this research. This person speaks the language

that was used to explain this research.

This person reads well enough to understand this form or, if not, this person is able to hear and understand when the form is read to him or her.

This person does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give informed consent.

This person is not taking drugs that may cloud their judgment or make it hard to understand what is being explained and can, therefore, give informed consent.

\_\_\_\_\_  
Signature of Person Obtaining Informed Consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Person Obtaining Informed Consent

### About the Author

Kathleen Fowler received a Bachelor's Degree in Special Education from the University of South Florida in 1993. She taught students with emotional or behavioral difficulties and learning disabilities for eight years in Hillsborough County, and earned a Masters in Special Education from the University of South Florida in 1997.

In 2003, she earned a Masters in Literature from the University of South Florida. While earning this degree, she taught Composition I and II at the university. She entered the Ph.D. program in Special Education at the University of South Florida in 2003 and served as an instructor while earning her degree. Her research interests focus on the transition experiences of young adults with emotional and behavioral difficulties, and qualitative research methods.