Discovering Themes: Disability Identity Development as it Pertains to People Born with Spina Bifida

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DISCOVERING THEMES: DISABILITY IDENTITY

DEVELOPMENT AS IT PERTAINS TO PEOPLE

BORN WITH SPINA BIFIDA

A Dissertation

Presented to the Faculty of

Antioch University Seattle

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In Partial Fulfillment

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By

Elizabeth Scriven

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DISCOVERING THEMES: DISABILITY IDENTITY DEVELOPMENT AS IT PERTAINS TO PEOPLE BORN WITH SPINA BIFIDA

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DOCTOR OF PSYCHOLOGY

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ABSTRACT

DISCOVERING THEMES: DISABILITY IDENTITY DEVELOPMENT AS IT PERTAINS TO PEOPLE BORN WITH SPINA BIFIDA

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To date, disability identity development is a highly understudied construct. There are many models of disability, each interpret disability through a specific lens, but do not address the influence of disability on identity development. The few theories of disability identity that do exist have not been widely adopted. In addition, there is a lack of empirical evidence to support them. Another difficulty is that these theories do not separate different disability groups. Rather, the theories are applied to a broad heterogenous group of disability types. This is a problem because each disability type is quite distinct from the others and therefore each disability requires its own developmental model. On the surface, alternate models of identity development, such as racial identity development, seem similar to what might be expected in the process of disability development, however, as of 2019, no such studies have been conducted or published. It is the purpose of this project to uncover themes of disability identity development as they pertain to people with spina bifida in order to build a framework for understanding the process of identity development in this population. A descriptive phenomenological methodology was used to conduct a thematic analysis of existing literature. A total of 79 articles were reviewed in detail, and common themes and connections were noted. Nine themes of identity development for
people with spina bifida emerged. The themes include: (a) employment, (b) family, (c) physical health, (d) psychological and mental health (e) view of disability, (f) sexuality, (g) impact of others, (h) psychosocial, and (i) transition. Each theme was deemed an essential element in understanding the process of identity development for those with spina bifida. This study was limited by the scope of literature reviewed as well as a lack of first-hand accounts of the identity process. This work is intended to be preliminary and to provide direction for further research. This dissertation is available on open access at Aura, http://aura.antioch.edu/ and Ohio Link Etd. Center, https://etd.ohiolink.edu/etd.

Keywords: spina bifida, identity development, disability, psychosocial, ableism
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INTRODUCTION

Disability identity development is a highly understudied construct. On the surface, it seems that disability identity development may have similar processes or patterns as ethnic and racial identity development, but to date there are no adequate models or theories to help make the comparison. In comparison, a myriad of research studies has been conducted on racial identity development theories. In a review of the literature, racial identity development theories presented by Sue and Sue (Sue & Sue, 2013; Salazar & Abrams, 2005), Cross (1978; Tatum, 1992), Helms (Helms & Carter, 1991; Tatum, 1992) and others who contributed to the dialogue predominated. Searches for “disability identity development” uncovered many models of disability, such as the medical or social model, but little could be located specifically regarding disability identity development itself. Models of disability are important, as they speak to the greater interpretation of disability, but they do not address the individual experience of disability identity in the way a theory of disability identity development would. According to Mpofu and Harley (2006), “there is at present no widely recognized theory on disability identity development” (p. 16). Though this statement was made 13 years ago, it holds true today; there is still no widely recognized theory on disability identity development. It is hoped the current research will provide the foundation on which theories of disability identity development can be hypothesized.

Racial Identity Development

Theories of identity development typically describe a process through which an individual moves through stages that allow him or her to achieve increasingly healthier states of psychological well-being (Mpofu & Harley, 2006). In general, models of racial and ethnic identity development explain how an individual gets comfortable in his/her own skin as a member of a minority group, living within a majority that is racially and ethnically different. As
a part of this discussion, it is germane to highlight several key racial identity development models including those proposed foundational theorists Cross, Helms, and Sue and Sue.

Cross’s model is specific to Black identity development and consists of five stages (Cross, 1978; Tatum, 1992). This model describes how Black identity moves from a subconscious awareness to conscious acknowledgement, to an intentional positive attitude towards being Black. Work done by Helms describes how White Americans become aware of racial identity. In her model, a White person starts with unawareness of racial bias, moving to awareness of racial bias, and concluding with an appreciation of racial differences (Tokar & Swanson, 1991).

The Racial/Cultural Identity Development Model (R/CID) has been put forth by Sue and Sue (2013). In this model, individuals start the process of identity development by internalizing the majority’s characteristics. They then move through a period of dissonance, followed by an integrated awareness of their identity. Of these three theories, R/CID is the most applicable to disability identity development as it describes a process of minority group identity development.

The R/CID model is more inclusive than both Cross’s and Helms’ models. Cross’ (1978) theory was written to describe the Black experience and Helms wrote to describe the White experience. Sue and Sue (2013) were more inclusive in their model as they state that the R/CID model can be applied to a variety of minority groups including the minority group comprised of people with disabilities. That said, the model still falls short in that it is too general and is written from a cultural perspective. Those with disabilities, though a minority group, are not a cultural minority group. In this author’s view, it seems intuitive that the experience of those with disabilities would be different from those without disabilities who make up ethnic minority groups. It can also be said that the minority group of disability is in itself multi-cultural as
disability is not ethnic specific. As such, the disability minority group is deserving of a theory or model of identity development specific to the people that it make up this group.

**Disability Identity Development**

There are many models of disability and proposed factors that influence identity development in individuals with disability. Models of disability include the medical model, social model, minority model, moral model, economic model, and spectrum model, to name a few (Langtree, 2010). Historically, the medical model has been used to frame many illnesses and disabilities. The medical model sees disability as a condition in need of fixing so the individual can be “normal.” The person with a disability is regarded as having a body that is abnormal, and thus inferior (Mpofu & Harley, 2006). When the medical model is the sole frame that disability is seen through, the person with disability often internalizes this view thus beginning to believe that they are broken and inferior to those without disability (Kinavey, 2007).

The social model was put forth in opposition to the medical model (Bampi, Guilhem, & Alves, 2010). The social model of disability sees disability as a category that is socially constructed (Darling, 2013; Shakespeare, 1996) through attitudes and environments. Instead of viewing the individual as needing to change, this model argues that society needs to change (Mackelprang & Salsgiver, 2009). This model avoids the problem of internalizing an idea of brokenness, however, it is just as narrow as it does not take into account individual traits of people with disabilities. In this model, if environmental factors were adapted and if society had more disability-positive attitudes, then the disability would be a non-issue negating ongoing medical issues, mental health issues, and other individual factors.

Both the medical and social models are applicable to this study, depending on a person’s stage of disability, whether he or she is new to the disability, the disability’s level of stability, and whether or not the individual is otherwise healthy. The medical model can be used to justify
interventions such as surgeries, physical therapy, orthotics and other medical interventions that may restore some level of bodily functioning. The social model might be used as an advocacy tool to allow better access to the community through the provision of curb cuts, inclusive programs, and awareness seminars to help change attitudes. However, they both offer only a narrow view of disability and do little to explain how an individual with a disability develops a sense of identity.

While models provide only a framework for understanding disability on a large societal scale, they do little in the way of explaining the individual experience of disability. For example, the medical model uses a medical framework to describe the disability’s relationship to the individual and others. The social model describes how a person with a disability interacts with society and how society diminishes or emphasizes the disabling condition. Neither of these models addresses the individual experience of disability identity. A disability identity theory would take into account the individual lived experience of having a disability and describe the process through which individuals with a disability incorporate the disability and other variables into how they see themselves.

Several scholars have tried to develop theories on the process of disability identity development. In the late 1990s, Gill (1997) proposed an integration model of disability identity. However, to date, it has neither been tested nor widely accepted. In 2004, a dissertation by Weeber, a doctoral student from North Carolina State University (Weeber, 2004), described a complex model of disability identity development. However, her model has not been tested by others. Both Gill’s theory and Weeber’s models apply to a generalized, heterogeneous disability group, meaning the individuals they describe have a variety of disability types. Each disability is quite distinct from other disabilities. For example, one physical impairment (e.g.: visual impairment) has a very different impact than another (e.g.: auditory impairment). In addition,
varying types of disabilities (e.g.: physical vs. intellectual) vary even further. Identity
development theories mix these disabilities, and thus do a great disservice to individuals by
failing to recognize the specific, idiopathic experience of the individual.

**Origins of the Present Study**

I am a person with a disability. I was born with a congenital disability called spina bifida
(SB). SB is explained in detail below, but here I wanted to briefly highlight some of the
impairments that are typically associated with SB. They include paralyzed lower extremities,
bowel and bladder incontinence (Lennon, Murray, Bechtel, & Holmbeck, 2015), impaired
sensation, orthopedic problems such as hip and knee contractures (Bellin et al., 2010), and sexual
dysfunction (Veenboer et al., 2013). There are also a variety of secondary issues related to SB
such as the need for tendon release surgeries, pressure sores, bladder and kidney infections
(Wagner et al., 2015), and spinal deformities, such as scoliosis and kyphosis (Thomson & Segal,
2010). I have experienced most of these at multiple points in my life. I know without a doubt,
these issues have influenced who I am today.

During my third quarter of my doctorate studies in Clinical Psychology, I was sitting in
class as we were discussing ethnic and cultural theories of identity development. As I was
listening to the lecture, I began to notice that there seemed to be many parallels between the
experiences these theories described and my own experiences. I found myself wondering if there
was a theory on disability identity development that would describe my experience as a person
with a disability. As I looked into it, I was sorely disappointed as there had not to date been a
widely accepted theory on disability development. Those that were offered seemed full of
problems and limitations that precluded them from being applicable to many individuals with
disabilities. So, I decided to take action and use my dissertation project to fill in what to me is a
vital gap in the disability literature. Since it is the parallels between my experience and cultural
and ethnic models of identity development that sparked my interest, I will start this next section by reviewing ethnic and cultural models of development.

**Spina Bifida**

At the center of this work is the birth defect spina bifida (SB), approximately three in 10,000 babies born each year have spina bifida (Wagner et al., 2015), making SB the second most common congenital birth defect in North America after congenital heart disease (Swartwout, Garnaat, Myszka, Fletcher, & Dennis, 2010). Medical advances have steadily improved survival rates since the 1950s. Currently, at least 85% of children born with SB survive to adulthood (Rofail, Maguire, Kissner, Colligs, & Abetz-Webb, 2014). Therefore, it is increasingly common for practitioners in a variety of human service fields to encounter people with SB. Thus, it is crucial that human service practitioners have an understanding of the biopsychosocial implications of SB so they can provide quality services to this population.

Spina bifida is Latin for “split spine” (Fletcher & Brei, 2010), a name that reflects a birth defect in which the spinal column fails to fully form and therefore is actually split. The condition develops within the first trimester of pregnancy. In typical fetal development, neural folds develop and meet at the midline of the back, forming the neural tube. The vertebrae also fully fuse at the posterior midline of the back, creating an enclosed tunnel down which the spinal cord can travel. For fetuses with SB, there is improper fusion of the neural folds and they remain connected to the ectoderm and epidermis. In addition, the bones of the vertebral column also fail to fuse, leaving the spinal cord vulnerable to injury. In other words, instead of forming an enclosed “O” shape, some vertebrae form a “C” shape that cannot fully shield the spinal cord. The resulting spinal cord damage is what causes paralysis and other physical issues. Damage due to this defect starts in utero, where the slightly acidic amniotic fluid acts as an irritant to the spinal cord. Traumatic birthing can also further the damage.
Severity of the condition depends on two factors: the type of SB and the level of defect and lesion, where the level of lesion refers to the location on the spinal column at which the defect occurs. The higher the lesion on the back, the more severe the implications and resulting disability. In order of severity, least to most, the SB types are occult spinal dysraphism, spina bifida occulta, meningocele, and myelomeningocele, also referred to as meningomyelocele (Spina Bifida Association). In occult spinal dysraphism, there is a dimple on the infant’s lower back with no other immediate symptoms. The second form, occulta, produces no visible signs and is often asymptomatic. According to the Spina Bifida Association website, approximately 15% of healthy individuals have this form of SB but are unaware of it. In a person who has the meningocele type, the spinal cord pushes through the spinal column but stays within a sac containing cerebral spinal fluid (CSF). The person may have minor disabilities but typically there is no permanent nerve damage. Myelomeningocele, or meningomyelocele, is the most severe type of SB, as well as the most common (Rofail et al., 2014). In this type, the spinal cord and other nerves are not contained in a sack of CSF. They come through the open part of the spine and when the defect is at its severest, may even protrude through an opening in the skin.

Etiology and neurophysiology. The specific cause of SB is unknown. Its occurrence is believed to be influenced by genetics and environmental variables, as well as maternal diet and medications during pregnancy (Rofail et al., 2014). One dietary supplement, folate sold as folic acid, has been found to prevent neural tube defects. When taken before and during pregnancy, folic acid can prevent 50–70% of these birth defects (Fletcher & Brei, 2010). Folic acid can prevent SB even when there is a strong genetic factor, such as a parent having the condition.

In addition to neural tube defects, other central nervous system changes occur early in fetal development. Spina bifida can be detected as early as 11 weeks, as can other neural changes that often accompany SB (Loureiro, Ushakov, Montenegro, Gielchinsky, & Nicolaides, 2012).
Loureiro et al. (2012) looked at brain scans of fetuses to characterize brain development in babies born with SB. They discovered that there is a reduction of CSF in the lateral ventricles, the roof of the third ventricle, and the aqueduct of Sylvius. They also found a reduction in diameters of the forth ventricle and cisterna magna, as well as an increased diameter in the brain stem. In some cases, the Chiari II malformation, a brain deformity, had also already developed.

Dennis, Nelson, Jewell, and Fletcher (2010) also reported gestational brain malformations in which the hippocampi are rotated outwardly and are laterally dislocated, and there is also abnormal sulcation in the mesiotemporal cortex, atypical development of the frontal lobes, and a reduction in white matter tracts. These malformations are not present in every case of SB but are fairly common and can cause many difficulties for the individual throughout life. These include social and cognitive difficulties, which can have ramifications for education, employment, and independent living later in life.

**Impairment and sequelae.** Numerous impairments are a direct result of SB, and there are many related secondary conditions. These impairments vary widely among individuals and may include paralyzed lower extremities, bowel and bladder incontinence (Lennon et al., 2015), impaired sensation below the level of lesion, muscle weakness; orthopedic problems such as hip and knee contractures (Bellin et al., 2010); and sexual dysfunction (Veenboer et al., 2013). In addition, 85–95% of individuals with SB have hydrocephalus that requires shunting (Jenkinson et al., 2011).

A secondary condition is defined as “those physical, medical, cognitive, emotional, or psychosocial consequences to which persons with disabilities are more susceptible by virtue of an underlying condition, including adverse outcomes in health, wellness, participation, and quality of life” (Wagner et al., 2015, p. 492). Secondary issues related to SB can be broken into two categories: physical and cognitive. Physical issues include tendon releases, pressure sores,
urinary tract infections, the need for shunt revisions (Wagner et al., 2015), and spinal deformities such as scoliosis and kyphosis (Thomson & Segal, 2010). Many of these secondary conditions, such as pressure sores and urinary tract infections, are preventable. For adults with SB, preventable secondary conditions are the cause of up to 47% of hospitalizations (Veenboer et al., 2013).

Cognitive secondary conditions are related to cases in which hydrocephalus or the Chiari II malformation co-occur with other brain structure changes. Hydrocephalus is a condition in which cerebral spinal fluid builds up in the ventricles of the brain, causing pressure. It is treated by shunting, a procedure that allows the fluid to drain (Mayo Clinic). The Chiari II malformation is when the cerebellum and part of the brain stem slip down into the foramen magnum, the hole at the base of the skull through which the spinal cord passes (National Institute of Neurological Disorders and Stroke). The cognitive difficulties these conditions can cause include learning difficulties (Rofail et al., 2014), Cocktail Party Syndrome (Tew, 1979), impaired cognitive accuracy, slowed reaction time, performance variability, and task consistency (Dennis et al., 2015). Other areas of general weaknesses tend to include those related to assembled processing, nonverbal IQ, reading comprehension, pragmatic language, math estimation, spatial relations, motor control, variety of memory, and executive functions that require organization and construction of information (Swartwout et al., 2010). These cognitive difficulties can make many tasks difficult and the overall impact can be substantial.

**Developmental differences.**

**Early childhood.** Lomax-Bream, Barnes, Copeland, Taylor, and Landry (2007) conducted a study on how SB impacts the first three years of child development. They found many differences between children with SB and typically developing (TD) peers. In general, children with SB demonstrated lower levels of functioning and slower rates of growth in
cognition and language. When motor skill development is measured and data points are graphed, their data produced a longer, less sloped growth curve than those of their TD peers. Children with SB took an average of three years to develop the motor tasks that their TD peers were able to master in an average of two years. These difficulties were positively correlated with lesion level as well as shunting in children with SB, such that those with shunts and higher lesion levels had poorer outcomes. School-aged children continue to have troubles with visual-motor and spatial skills, problem solving, math performance, attention regulation, language acquisition, adaptive behavior, abstraction, sequencing, planning, and mental flexibility (Lomax-Bream et al., 2007). These challenges can make everyday classroom learning challenging.

**Middle childhood.** Cocktail Party Syndrome is a language disorder specific to children with hydrocephalus and affects many children with SB (Tew, 1979). Tew (1979) describes children who have Cocktail Party Syndrome as “[m]entally retarded but educable, with a peculiar contrast between a good ability to learn words and talk referred to as syntax abilities, and not knowing what they talk about. They love to chatter but think illogically” (p. 89). Children with this syndrome have excellent syntax but cannot use language creatively. They often have impaired concentration ability, which impedes their ability to track and follow along in a conversation. Overall, they have lower Wechsler Intelligence Scale for Children (WISC) scores in perception and reasoning as well as impaired social skills. Tew (1979) postulates that positive reinforcement from adults often perpetuates the syndrome, since such children may be praised for their syntax abilities. However, once a child with Cocktail Party Syndrome enters school and is admonished for talking inappropriately, the disorder diminishes and typically is no longer present by adolescence.

School-aged children with SB often receive occupational therapy (OT) or physical (PT) therapy services through the school. Many elementary age students with SB still have difficulties
with their upper limbs, such as issues with control, organization, and quality of gross and fine motor movements (Lomax-Bream et al., 2007). Occupational and physical therapy can help them gain coordination and strength in the parts of their body without impairments. These therapies also help teach skills such as transfers, balance, stretches, and many other important skills a child with SB will need to know (The Sydney Children’s Hospitals Network).

In addition to a variety of physical issues, people with SB often have interpersonal difficulties as well. A study by Devine, Holmbeck, Gayes, and Purnell (2011) compared the perceived quality of the relationship between youth with SB and a TD friend. The youth with SB rated their relationship as closer than did the TD friend. This study also revealed that youth with SB experienced lower levels of companionship, security, intimacy, and closeness through their relationships. The authors attributed this to several factors that are common to youth with SB: social immaturity, more passive interaction style, and fewer friends compared to TD peers. Youth with SB are also less likely to have social contact outside of school, have a tendency to withdraw from social situations, and lack initiative in establishing contact with a friend. Holbein et al. (2014) ascribed poorer peer relationships to less socially competent behaviors and lower social dominance. In addition, abilities in areas such as collaboration, clarity of thought, explanations of thought, confidence in stating opinions, and quality of verbal usage were poorer in kids with SB, which impeded conversational abilities and social relationships.

**Adolescence.** Teenagers with SB face unique developmental and social challenges. “Adolescence is a transitional period of human development marked by significant changes in biological, cognitive, social, and emotional functioning” (Lennon et al., 2015, p. 944). When an adolescent has a disability such as SB, they have to navigate the typical teen transitions as well as disability-related issues. They may find themselves dealing with disability-related ailments, such as pressure sores, surgeries, or infections. In the United States, it is estimated that there are
24 million missed days of school annually for disability-related reasons for children with activity-limiting disabilities (Edwards, Patrick, & Topolski, 2003). Peers act as role models and provide feedback on socially acceptable behaviors, appearance, and identity (Sales, 2011). Whenever a student with SB misses school, they miss out on opportunities to participate in the daily exchanges in which this crucial feedback occurs.

Adolescents with SB may also perceive themselves as dissimilar to TD peers (Kinavey, 2007). Oftentimes, they do not attain status within the “in-group” of choice because of the negative views and stereotypes of them held by “in-group” members (Zambo, 2010). Feeling out of place can lead to low self-esteem and poor body image. Having a low social status also can make youth with SB targets for hostility and bullying from peers (Kinavey, 2007). For example, at least 25% of youth with SB report being bullied because of their disability (Hayter & Dorstyn, 2013) whereas only 19% of TD youth in grades 9-12 experience bullying (stopbullying.gov). Thus, much of the feedback youth with SB may get from peers is negative and can lead to internalized negative self-perception.

Anderson (2009) notes that role models and mass media play a large role in adolescent identity formation and development of self-concepts, especially for adolescent girls. Anderson reports that adolescents with disabilities have few role models with disabilities in the media with whom to identify during this critical time of self-identity development. Kinavey (2007) also notes that finding role models in the community, both at school and in the neighborhood, is difficult and often impossible. This lack of role models can make the already difficult task of navigating the transitional years of adolescence even more problematic.

**Treatment.** There is no curative treatment for SB. However, there are many interventions used to manage the associated ailments. Soon after birth, the defect itself requires surgical repair. The specific surgical procedure used depends on the severity of the deformity. If
a baby develops hydrocephalus, shunting is also performed shortly after birth (Dennis et al., 2010). The infant is discharged only when medically stable, after surgical wounds have started to heal.

Throughout life, those with SB may seek treatment for secondary conditions of SB. Rofail et al. (2014) list several interventions that have been helpful in treating people with SB. Physical therapy is often utilized to help develop upper body muscle strength and coordination, as well as to keep paralyzed legs stretched out to prevent muscle contractures. Catheterization and sometimes a bladder diversion surgery are used in combination with antibiotics as needed to prevent bladder and kidney infections. In cases of hydrocephalus, shunt revisions may need to be performed periodically throughout life (Dennis et al., 2010). Wound care may also be needed from time to time, since those with SB are more prone to develop pressure sores (Liptak et al., 2015). Lastly, counseling can be helpful to improve self-image and reduce the internalizing of barriers.

There are also many orthopedic and surgical interventions that aid the well-being of those with SB. Tight hips, knees, and ankles may need tendon release surgery. Spinal issues such as a tethered spinal cord, scoliosis, and kyphosis may require surgery (Thomson & Segal, 2010). A tethered spinal cord occurs in approximately 20% of individuals with SB and is caused by bone fragment around the site of the SB lesion piercing the spinal cord. Surgery is required to release it. Scoliosis and kyphosis are both spinal deformities. In scoliosis, the spine is curved from side to side, while in kyphosis it curves outward, creating a hunched back. In both cases, surgery is required to stabilize the spine with surgical rods so that the condition will not get worse (Thomson & Segal, 2010).
Durable medical equipment is often used to provide support for individuals with SB, especially in mobility needs. The insurance company Blue Cross Blue Shield defines durable medical equipment as:

Durable Medical Equipment (DME) is any equipment that provides therapeutic benefits to a patient in need because of certain medical conditions and/or illnesses. DME consists of items which: are primarily and customarily used to serve a medical purpose; are not useful to a person in the absence of illness or injury; are ordered or prescribed by a physician; are reusable; can stand repeated use, and are appropriate for use in the home. (Blue Cross Blue Shield, 2016)

For people with SB, DME includes a variety of tools used to improve daily living. Equipment such as wheelchairs, walkers, crutches, leg braces, hospital beds, pressure reducing cushions and mattresses, and lift assist devices are some examples.

The support of a multidisciplinary team can be especially helpful in treating people with SB. Children with SB are often surrounded by a team of medical professionals before they are even born (Veenboer et al., 2013). However, many adults do not have the benefit of this team care approach. Veenboer et al. (2013) found fewer than half of young adults age 16 to 25 with SB had a multidisciplinary support team and only one-third of older adults with SB had access to a multidisciplinary team. This study highlighted the need for adult multidisciplinary teams, since over 40% of participants had been in the hospital in the last year for a preventable condition. Ideally, preventative care received in a multidisciplinary team setting would reduce the number of preventable hospitalizations as potential issues would be treated prior to causing problems. In addition, 85% of participants had a new health concern related to physical, musculoskeletal, neurological, gastro-intestinal, or urological issues. Veenboer et al. (2013) stress the importance
of a team comprising a primary care provider, specialists, a social worker, and a counselor or psychologist, as well as a psychiatrist, in order to provide the most well-rounded care.

Project Purpose

There is a striking paucity in the literature regarding disability-specific identity development and factors influencing such (Bellin & Rice, 2009; Dunn & Andrews, 2015; Lau & Ng, 2014; Mpofu & Harley, 2006; Noonan, 2004; Yoshida, Li, & Odette, 1999). Clearly, further research is desperately needed in this area, as little is understood about how a person with a disability comes to positively incorporate that disability into his or her self-identity. In addition, a better framework for understanding disability identity development is needed in order to provide effective counseling treatment. Strike, Skovholt, and Hummel (2004) also suggest although many psychologists perceive themselves as capable of serving people with disabilities, there is a gap between self-perceived competency and knowledge, and actual competency and knowledge. Their research underscores the fact that counselors do not have a strong understanding of disability identity issues. As such, the hope of this study is to provide the framework for the development of a theory of identity development that will guide professionals, caregivers of people with physical disabilities, and allow them to close the gap in perceived understanding and actual knowledge.

Overview of Methodology

The purpose of this project is to review existing literature, in detail, searching for common themes and connections using a descriptive phenomenological method. The phenomenon under investigation will be the development of identity among individuals who have spina bifida. This current study seeks to identify common themes and ideas in the literature, therefore constructing a comprehensive model of disability identity development.

The literature review will aim to answer the following questions:
1. What has been described in the literature about the experience of those with congenital physical disabilities in terms of their personal disability identity development?

2. What are the broader contexts and situations that have influenced this process?

To collect data to form a theory of disability identity, Giorgi’s (2009, 2012) descriptive phenomenological method will be implemented. The result will hopefully reveal key aspects of the essential process of disability identity development.
LITERATURE REVIEW

Identity is a concise way for an individual to say who they are. This sounds deceptively simple in that it lacks an explanation of how the person came to understand who they are, and how identity developed to make one the person they are today. These are difficult questions psychologists have been attempting to answer since the birth of psychology. Early psychologists, such as Freud (Fiore, 2011) and Erikson (Erikson, 1984), observed and postulated how children and adults develop over time. Both posited theories of human identity development. Later Cross (1978), Sue and Sue (2013), Helms (Helms & Carter, 1991), and others brought multicultural perspectives into identity development. Rather than simply asking how people become who they are, they asked how identity development differs for a person when they belong to a specific ethnic group. More recently, other minority groups such as LGBTQ individuals (lesbian, gay, bisexual, transgender, questioning), women, and people with disabilities have asked versions of the same question.

This literature review will provide a map to understanding identity development with the goal of cultivating an understanding of disability identity development for people who have congenital physical disabilities. At present, there is no model of disability identity development solely addressing this group of people. Rather, disability identity research typically uses heterogeneous groups of people with disabilities, including all physical disabilities (acquired and congenital), visual and hearing impairments, autism, and intellectual and developmental disorders. As each of these subgroups of disability is very distinct, it cannot be overstated that each individual within this heterogeneous group develops uniquely. Despite the obvious, however, disability identity development continues to be explored as if all disability identity develops the same way.
Identity Theory

There is a paucity of understanding and research on the topic of disability identity development in general, let alone when looking at one disability group. Given that ever since Freud, the Father of Psychology, started publishing his thoughts on the psychology of identity development, scholars have been offering hypotheses on how people develop a sense of identity. As individual identity theory developed and evolved, it began to incorporate the social influences of identity development. Then in the 1960s and 1970s, ethnic and cultural identity models began emerging as the Civil Rights Movement came to fruition (Reynolds & Pope, 1991). As of 2007, more than 22 models of ethnic and cultural identity development had been created (Ponterotto & Park-Taylor, 2007). However, there are only a few models of disability identity development, all of which seem riddled with problems. Though there are significant distinctions amongst different types of disabilities (e.g., cognitive impairments, physical disabilities, visual impairments, congenital disabilities, and acquired disability), none of the current models or theories takes these differences into account. Rather, they group all disability types together. The present study hopes to begin to remedy this problem by only referencing the experiences of people born with a physical disability.

A Historical Perspective

A brief overview of the historical development of identity theory is called on in order to best understand how psychology today understands identity development. Early Western culture placed high value on capitalism, urbanization, secularism, and individualism (Cushman, 2011). The first identity development theories tend to reflect these values, as the process is described as determined by internal factors such as the id, ego, and super ego, or with the resolution of an internal crisis. In the mid-1900s, Hermeneutics began to influence how the world of psychology understood human behavior, including identity development (Cushman, 2011). Hermeneutics, as
explained by Cushman (2011), requires psychology take into account multiple perspectives all of which are influenced and entangled with each other. Thus, the individual cannot be separated from the environmental and social influences in which they develop. Hermeneutics is reflected in the ideas of Bronfenbrenner and others who contributed to an intersectional understanding of the process of identity development.

Throughout the 1800s, people with disabilities were often referred to as “infirm” or “cripples” (Sales, 2007, p. 47). Europe has a long history of unequal treatment for people with disabilities. During the 1800s, the general population tended to have an attitude that viewed people with disabilities as “pathetic and pitiable” (Ali, 2013, p. 8). The Poor Law Amendment Act of 1834 resulted in more people with disabilities being forced to live in institutions (Ali, 2013). At the same time, some distinctions began to be made among various disability groups (Ali, 2013; Sales, 2007). According to Sales (2007), those with visual and hearing impairments witnessed the greatest amount of change, as specialty schools were established to meet the special needs of these groups via the 1893 Elementary Education Act in Europe (Ali, 2013). Often the schools for the Deaf and for the Blind were boarding schools where people were sent to live until they graduated. In addition, throughout Europe, there existed a bias that people with physical disabilities were incapable of caring for themselves and thus required additional care. This care was provided by family or hospitals often referred to as “the poor farm” (Sales, 2007, p. 48), and many people with disabilities or mental illness were institutionalized to be kept out of the public eye. The Idiots Act of 1886 allowed for this and also attempted to categorize people as idiots, imbeciles, and lunatics (Ali, 2013). Since people with disabilities were removed from mainstream society, these early identity development theorists had little interest in considering the development of people with disabilities; people with disabilities were out of sight and out of mind.
**Freud.** Sigmund Freud was born in Austria in 1856 and received his medical degree in 1881. Growing up and being trained as an MD in Europe, he likely would have adopted many of the attitudes, thoughts, and beliefs about people with disabilities. Early in his career, Freud was intrigued by the cause of neuroses. He later became the first to describe human identity development from a psychological framework (Fiore, 2011). He posited that a person’s identity is influenced by the id, the ego, and the superego. The id, a construct with which babies are born, is said to drive all of life’s basic instincts such as the need for food, comfort, and nurturance. Freud (1923/1989) described the id as containing the pleasure-principle, where passions “reign supreme” (p. 8).

Freud maintained through the superego, which functions as an internal conscience, individuals develop a sense of right and wrong (Fiore, 2011). This sense of right and wrong is internalized and used to guide behavior. The superego, which Freud also called the ego-ideal, tells the individual what he or she values and considers ideal (Freud, 1923/1989). Lastly, Freud asserted the ego as the central part of personality (Fiore, 2011). It is based in rationality and helps balance the id and the superego. According to Freud, the ego organizes mental processes and confers individuals with reason and sanity.

Freud’s ideas gave birth to the field of psychology and revolutionized how people thought about the self and human behavior. Yet, his ideas were steeped in European ideas about those with disabilities. At that time, many people with disabilities were institutionalized and not in public view. Thus, his ideas did not reflect the experiences of people with disabilities. This is not to fault Freud; his ideas had a great impact and some practitioners still practice Freudian Psychoanalysis today, however he neglected to incorporate the disability experience.

**Erikson.** Erik Erikson was born in Germany in 1902. He became trained as a psychoanalyst, influenced by Freud, through his training at the Vienna Psychoanalytic Institute
and began his career in 1936 in the United States. Thus, like Freud, he was influenced by turn of
the century European ideas about people with disabilities. However, unlike Freud, Erikson did
his work in the United States, though many people with disabilities were also institutionalized in
the United States, things were also starting to change. Around that time, the U.S. was passing
legislation to help provide vocational training for those with disabilities through the Civilian
Vocational Rehabilitation Act of 1920. A publication of the Massachusetts Office on Disability
(2016) offers a timeline of important dates for people with disabilities in the United States. In the
1930s, the U.S. saw the signing of the Social Security Act, which provided federal assistance to
adults with disabilities as well as the founding of the National Foundation for Infantile Paralysis,
which was later renamed the March of Dimes. During the late 1930s and into the early 1940s, the
world also endured thousands of “mercy killings” of people with disabilities performed by the
Nazis. Erikson would have been influenced not only by discriminatory legislation and attitudes
but also by the positive shifting attitudes in the U.S and the pro-disability legislation that was
passed, hopefully leading to a more balanced perspective.

Erikson’s ideas differed from Freud in that rather than focusing on intra-psychic
structures (i.e., the id, ego, and superego), he emphasized extra-psychic influences such as the
complexity of an individual’s relationships within his or her environment (Mitchell & Black,
1995). For this reason, his ideas were deemed a psychosocial theory of development. Based on
his studies of people from a variety of cultures, he theorized individuals move through a series of
eight stages termed crises (Fiore, 2011). Erikson (1984) referred to his theory as an “epigenetic
scheme” (p. 157), which meant there are “life cycle” (p. 157) forces at play throughout life that
never stop influencing an individual’s identity. In each stage, the individual experiences a crisis
that must be resolved. Erikson explained that each stage has a syntonic (positive) and a dystonic
(negative) quality. In a healthy individual, the syntonic component would outweigh, or at the
very least, balance the dystonic component, although the dystonic aspect is never completely absent. Through a positive resolution of each stage, the individual develops a newfound strength.

To help the reader visualize the process, Erikson (1984) developed a chart that can be found in Appendix A, although the following is a brief description of the lifespan psychosocial developmental process. Throughout life, one goes through eight life stages, each with a unique crisis, which needs to be resolved. When a person positively resolves a given life stage’s crisis, he or she gains a specific strength. Erikson explained each strength is already in rudimentary form before each crisis is reached, but through the stage-specific crisis, it is able to come to full fruition. After it has been fully developed, it then becomes available for use in each of the next crises. For Erikson, identity development is a lifelong process that progresses with each crisis.

Erikson’s ideas seem to ignore the explicit disability experience. However, where Freud did not leave room in his ideas to account for the influences of disability, Erikson managed to leave a little room for it. In his psychosocial description of each crisis and how an individual comes to resolving each, the disability experience is implicitly involved. At each crisis stage of development a person with a disability cannot help being influenced by the disability as they navigate their environment. The impact of the “life cycle” forces an individual with a disability to be influenced by their disability status. Therefore, Erikson’s theory does leave room for the disability experience. However, it does not explicitly address the impact of disability, or attempt to explain how disability status impacts the effect of “life cycle” forces, or how an individual with a disability interacts with their environment. Thus, his theory also falls short.

**Bronfenbrenner.** Urie Bronfenbrenner was born in Soviet Russia in 1917 and moved to the United States with his parents in 1923. Bronfenbrenner was influenced by his father, a neuropathologist, who worked with people with developmental disabilities. Bronfenbrenner was especially impacted by his father’s concern about how society’s views and behaviors impacted
these individuals. He began his work in the 1940s, first providing psychological services for the Army, then becoming faculty at Cornell. Bronfenbrenner was also undoubtedly influenced by the political climate in the United States. The late 1940s saw the founding of the Rusk Institute of Rehabilitation, which helped rehabilitate injured soldiers, and the 1950s saw the start of the barrier-free movement, which introduced barrier-free standards for buildings (Massachusetts Office of Disability, 2016). Bronfenbrenner published works throughout the 1970s and thus would have also been influenced by the Vietnam War, the Civil Rights Movement, and the Rehabilitation Act of 1973, which addressed issues of civil rights and equal access to public spaces and buildings for people with disabilities (Sales, 2007).

**The Ecological Model.** Bronfenbrenner developed an ecological systems approach to describe human identity development (Bronfenbrenner, 1978; Lau & Ng, 2014). Through his work, he identified biological, psychological, and social aspects of development, and stated the interactions of these factors over time continuously shape a person’s identity. There are four major components of his model. The first component is proximal processes, which are the reciprocal interactions a person has with the people around him or her. The next component he described is the person as an individual. This includes his or her temperament, personality, and mood, which influence all of his or her interactions. The third component is context, which includes environmental factors that shape development. Lastly is the component of time, which Bronfenbrenner felt was important because the passing of time influences how people interact with the people and things around them (Fiore, 2011). In addition to the aforementioned components, Bronfenbrenner viewed the overall ecological system as a set of nesting sub-environments depicted as concentric circles. Each of these sub-environments operates independently of the others yet each also influences the others (Lau & Ng, 2014). These sub-
environments include the microsystem, mesosystem, exosystem, macrosystem, and chronosystem (diagram located in Appendix B).

As the sub-environment moves farther from the center it grows larger and contains systems that are more varied and complicated (Fiore, 2011). The microsystem is the “pattern of activities, roles, and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics” (Lau & Ng, 2014, p. 426). According to Lau and Ng (2014), the emphasis of this model is on the lived experience of the individual. The next layer, the mesosystem, consists of the interactions of two or more settings in which the individual actively participates: for example, the processes that take place between a family setting and a school setting (note the double headed arrows in the diagram). At the third level, the exosystem, the individual is not actively involved in a setting but is still affected by it. For example, consider the politics around the Affordable Care Act, colloquially known as Obamacare. A developing individual is affected by the act regardless of whether or not they were involved in writing or voting for the Obamacare laws, as he or she may now have access to healthcare. The fourth layer, the macrosystem, encompasses values and beliefs of the culture in which the person develops. Finally, the last and outermost level is that of time. Bronfenbrenner believed that both the environments and the developing individual change over time and continue to develop (Lau & Ng, 2014). The interactions among these layers, then, are what shape a person’s identity.

**Bronfenbrenner and the disability experience.** The dialog of intersectionality created by Bronfenbrenner’s Ecological Model by far goes the furthest in incorporating the disability experience. The Ecological Model describes a series of interactions that start at the individual level. The individual level would include aspects of that specific individual such as stature, race, ethnicity, disability status, socio-economic class, and other individual variables. These individual
variables interact with the larger social levels and variables. Thus, it is assumed disability would
be a key moderating factor in all of the individual with a disability’s interactions. However,
Bronfenbrenner too, does not explicitly discuss how disability status factors into his model. It
leaves those with disabilities assuming disability factors into the interactions the model describes
rather than explicitly showing them how disability factors in.

Post-Modern Theories of Identity Development

As noted previously, it was not until a Hermeneutic perspective was used that psychology
began to realize identity was not an internal process. Rather, it was a relational process
influenced by internal, environmental, and societal factors. In the post-modern era, the last half
of the 20th century (Cushman, 2011), theories of identity development began to further expound
on the intersectionality of individual roles and responsibilities, as well as social groups to which
they belong. During this time, much of what was happening in the world of disability was due, in
part, to the Vietnam War, as many soldiers were returning disabled from injuries. Historically,
war is what has pushed the disabilities movement forward. President John Adams signed the first
piece of legislation for the aid of United States Seamen in 1798. This bill provided funding to
help treat sick seamen. The Civil War resulted in 30,000 amputations for U.S. veterans, which
highlighted the needs of those with disabilities. In 1890, the Dependent and Disability Pension
Act was signed into legislation which provided an annual pension for veterans who served in the
Union Army (Blanck & Millender, 2000). The first Vocational Rehabilitation legislation was
passed in 1918 following World War I. This bill and its amendment sought to help veterans
become employable after their service, it also established temporary and permanent disability
compensation rates (U.S. Department of Veterans Affairs). In the 1950s, disabled veterans, along
with other people from the disability community saw the development of “barrier-free” building
standards. The first set of barrier-free standards was not published until 1973, however by that
time there were 49 states that had already created disability legislation (The National Consortium on Leadership and Disability for Youth).

In the 20th century, the number of those with disabilities in the United States continued to grow, and events such as deinstitutionalization and the passing of the Rehabilitation Act during the 1970s pushed disability into public awareness (Sales, 2007). Deinstitutionalization encouraged the discharge of long-term residents from hospitals and institutions in order to reside back in their communities (Sales, 2007). This policy was prompted due to a lack of funding for, and often horrible conditions within, state run institutions (Dumont & Dumont, 2009). Instead, relying on Social Security payments, people with a wide range of disabilities were forced to live back in their communities, with family, or in independent living centers (Sales, 2007).

It was during this same time that Beatrice Wright, a psychologist who worked in the field of rehabilitation psychology, first published her thoughts on psychology and disability in a book entitled Physical Disability: A Psychological Approach (1960). She was one of the first, if not the first, to situate disability as a societal issue by describing environmental, attitudinal, economic, and educational barriers that emphasize the shortcomings of the person with a disability (Wright, 1960). Dr. Wright referred to these shortcomings as handicaps and they described the interaction effect that the disabling condition had with the context of environment, thus further limiting those with the disability. For example, if a person who used a wheelchair encountered a set of stairs, this would be an environmental handicap, as the stairs interact with the wheelchair use and limit access to a building. She also emphasized the importance of language and the impact language can have on how people view themselves and others, thus she was a strong advocate for “people first language” and used it in her writing.

The Rehabilitation Act of 1973 impacted disability rights in several important ways. First, the Act broadened the definition of “disability” to include a physical or mental conditions
that impair major life activities, having a record of such impairment, or being regarded as having such an impairment (Sales, 2007). Prior to this broadened definition of “disability” the term only applied to those with physical disabilities, blindness, or deafness (Sales, 2007). Sales (2007) reported that the 1973 Rehabilitation Act also mandated nondiscriminatory hiring practices in federal institutions and accessibility standards in public architecture and transportation, as well as broadened affirmative action to include people with disabilities. In addition, it protected the rights of children with disabilities to receive public education. Lastly, it set the stage for the American with Disabilities Act of 1990, which is the current civil rights legislation for people with disabilities.

The American with Disabilities Act (ADA) expands on the Rehabilitation Act. It uses the same definition of disability but includes contagious diseases such as HIV in its definition of disability. The ADA is broken into five titles, each protecting rights in different areas of life and social spheres (Sales, 2007). Title I protects the rights of an individual with disability to be employed. Title II requires accessibility in government-run services including facilities, programming, and transportation. Title III prohibits discrimination in privately owned public accommodations such as hotels, banks, and event centers. Next, Title IV provides access to telecommunications and radio, which is often done by way of TDD devices. Finally, Title V provides guidance for people with disabilities who think they have been discriminated against and want to take action (Sales, 2007).

Identity Theory and Social Identity Theory. Situated between the Rehabilitation Act and the Americans with Disabilities Act are Identity Theory and Social Identity Theory. These theories on identity development focused on which roles an individual ascribed to, and to which
social groups they belonged. They were not tailored specifically for people with disabilities, but they allowed more room for disability to be a factor in identity development.

According to Identity Theory, an individual’s identity is a collection of role identities that are self-defined by roles a person occupies (Hogg, Terry, & White, 1995). People label themselves and others according to the positions they hold (Stets & Burke, 2000). The labels then have a meaning and come with a set of expectations for behavior. Most role expectations are predetermined by the societal context in which the person lives (Hogg et al., 1995) and can be reduced to a set of fixed expectations resulting in socially appropriate behavior for an individual in that role. In identity theory, the core of a person’s identity is that of the role the individual plays. For example, a person in a student role is expected to go to classes, sit still and listen in class, study, and learn the material they are being taught. In addition, social behavior is explained as the reciprocal relationship between the self and society (Hogg et al., 1995). Being able to carry out a role entails being able to fulfill the expectations associated with that role, and using the environment to obtain the resources necessary to maintain the role (Stets & Burke, 2000). An individual might occupy as many roles as there are groups to which he or she belongs. The roles are made meaningful not only individually but also by way of the other roles with which they interact. For example, the meaning of the student role for an individual is made more meaningful when interacting with a person in the role of teacher. What makes identity theory different from social theory is that all labels and roles are self-defined rather than defined by society (Hogg et al., 1995).

Social Identity Theory is a social psychological theory that takes into account intergroup relations, group processes, and the social self (Hogg et al., 1995). Stets and Burke (2000) define it as “a person’s knowledge that he or she belongs to a social category or group” (p. 225). These social categories only exist as part of a larger social structure and in relationship to other social
categories. Within social identity theory, a person is defined by the characteristics of the group in which he or she feels he or she belongs (Hogg et al., 1995). When an individual claims a certain social identity, they claim there are commonalities with a larger group of people. Social identity groups include categories such as nationality, gender, ability or disability, etc. At its core, social identity theory is about intergroup relationships, especially the relationship of the in-group with out-groups (Stets & Burke, 2000).

Identity Theory and Social Identity Theory work in tandem, as people have roles and belong to groups concurrently (Stets & Burke, 2000). These theories apply to those with disabilities as they also have other roles and belong to other social groups, however, disability status often complicates the roles and often gets in the way of participating in both roles and social groups. For example, a study by Edwards et al. (2003) reported that 46% of adolescents with disabilities had missed social activities that they regularly participated in due to disability-related issues. This is in comparison to a group of peers without disabilities who only missed social activities 16% of the time. Both Identity Theory and Social Identity Theory assume that “typical” participation in roles and in social groups is possible, however, disability gets in the way of “typical” participation in roles and social groups. The predetermined expectations of roles can cause great difficulty for people with disabilities, as the disability may limit the roles they have access to or their ability to carry out the duties of a given role. Social Identity Theory assumes that people with disabilities participate in larger social groups. In many cases this may be true. However, disability status may also limit a person with a disability’s ability to participate in a larger social group, such as in the example cited above. People with disabilities may desire to belong to a social group consisting of people with similar disabilities, but in many areas such a group does not exist (Kinavey, 2007). Neither of these theories do an adequate job of making room for disability status, rather they have the potential for further stigmatizing and ostracizing
those with disabilities, especially if the disability status is internalized or keeps the person from participating in the desired social groups.

People tend to internalize messages they receive from the society in which they live, including those with disabilities. This often occurs at an unconscious level and can result in the individual downplaying their physical disability and striving to fit in (Kinavey, 2006). The idea of internalized marginalization is not new. Many of the existing models of identity development found in LGBTQ and racial identity development models incorporate it (Salazar & Abrams, 2005). Internalized marginalization needs to be incorporated into disability identity development, the fact that it is not incorporated into Identity Theory or Social Identity Theory makes them inadequate to describe the disability identity development experience.

People with disability have a long history of internalizing marginalization. People with disability have been told that they are not fit enough to live with their family but must be sent away (Dumont & Dumont, 2009). They have been told they need to rely on the “poor house” because they are not functional enough for the workforce. They have been told that they are incapable of taking care of themselves and need to be dependent on others for their care and well-being. These internalized social messages can create much confusion and internal tension for the individual with a disability. Through lived experience, the person with a disability may know that they are capable of working, that they do have value to their family, and do not need to rely on caregivers for their well-being. This experience is in direct contrast to the societal message they have likely always heard. The stress caused by this, and the energy used to make the effort into “passing as normal” (Hammar, Ozolins, Idvall, & Rudebeck, 2009) in order to fit in with their peers, has been linked to negative self-appraisal (Appleton et al., 1996).

Many of the assumptions encapsulated in identity development models assume that marginalization is in fact internalized. They describe a process in which, as a person continues to
develop, there are shifts in their perceptions due to the societal messages mentioned above, which result in a cognitive dissonance (Salazar & Abrams, 2005) that is a disconnect from what they know and what they are told. This can be very confusing, and cause internal conflict and tension, as the person with a disability struggles with the two messages and how much of either is true. Over time, as these messages get internalized, they lead to increased risk of developing depression (Kinavey, 2007), anxiety (Holmbeck & Devine, 2010), substance abuse (Sales, 2000), psychological insecurity, and self-loathing (Rembis, 2009). Therefore, it is important for a theory on disability identity development to discuss and describe the complications that disability has on one’s roles and group memberships. It is the hope of this present research to identify the themes pertaining to the effect of disability on role fulfillment and social group participation for people with disabilities. In identifying the themes, it will be possible for future research to incorporate them into new theories and models of disability identity development. Doing this will further integrate people with disabilities into the psychological research. It will give professionals and laymen a better understanding of the disability experience which will allow them to better empathize with people who have disabilities.

Recent developments on identity. A special edition of Developmental Psychology was devoted to articles pertaining to identity development process and content (2017). In this edition, several articles proposed multi-level models of identity development that incorporate the many components of identity and the levels in which they operate as well as their interrelationships with each other. One of the purposed models seems especially applicable to the framework necessary to hold a discussion of disability identity development as it pertains to people with spina bifida. This model understands identity as an integrated developmental process that is situated within a context (Galliher, McLean, & Syed, 2017). Rather than naming their model, the authors refer to it as “A multilevel model of identity content in context” (p. 2013).
In this model, the content of identity is comprised of a variety of components such as personality, values, religion, disability status, gender roles, and much more. The content areas of identity are arranged within levels as they relate to the proximity of the individual themselves, much like Bronfenbrenner’s Ecological model (Bronfenbrenner, 1978). At the outside level are more distal components of identity such as culture and historical context. The next level contains the various social roles and the contexts which contain them. At the center are the multiple intersecting domains that a person navigates through on a daily basis. Situated outside of the three inter-nesting levels are the everyday experiences, the microcontent, and the behaviors of the individual, where all the different components intersect and influence each other. This model is developmental in that understands that all the factors and variables contained within it affect the individual from the moment the child starts developing. Even a very young child cannot help but be affected by culture, family values, and other content of the outer most level. As they grow and develop, they begin to have more defined roles and are more heavily influenced by their everyday experiences. (See Appendix C for an illustration of this model).

This model utilizes Erikson’s idea of identity configurations, which were ways people used to manage and navigate the multiple conflicts faced throughout development. There are three classifications of identity configurations: conflict, compartmentalize, and coherence. Conflict occurs when two or more components of an individual's identity do not mix or contradict each other. Compartmentalizing is when an individual boxes in different identity components to minimize the conflict they experience. For example, conflict might arise when a person with a disability has compartmentalized their disability as separate from their role as student. Conflict could occur in several ways, perhaps a secondary health concern occurs causing the person with a disability to miss class or perhaps the class that is needed is held in an inaccessible location. In either of these situations, the disability that the individual works so hard
to compartmentalize breaks loose of the containment and causes difficulty for the individual in the role of student. Coherence occurs when the different components of an individual’s identity co-exist, and are integrated to the extent that an individual experiences “a subjective sense of invigorating sameness and continuity” (Galliher et al., 2016, p. 109). The goal in healthy identity development is for the various roles of an individual, the relationships between roles and domains, and the interrelationships between the levels of identity to coexist in cohesion. When cohesion exists between the pieces and parts, a person has a stable sense of who they are, which they are able to communicate to themselves and others (Galliher et al., 2017).

The outer most level is that of culture and historical context (Galliher et al., 2017). The authors describe this level as providing the historical and political context as well as describing the structural factors of a specific society. This includes understanding the systems of power and privilege that allow or deny access to resources, social status, and social capital. Here is where the conversation on the historical experience of disability is situated as well as the conversation on ableism and its impact on those with people who have disability. How power and privilege and abilistic ideas effects those with disability will be explored in detail in the discussion section of this work. At this level, those with disabilities must find a way to achieve a positive sense of self to do this they may be compelled to compartmentalize their disability status to minimize the impact it has on their ability fit in and be “normal.”

The second level is that of social roles, which describe the relationships in which an individual develops and navigates the path to their identity. Roles a person might play include sibling, child, parent, professional, colleague, spouse, student, and any and all roles that can be occupied in a social context (Galliher et al., 2017). These roles often get internalized and become a part of a personal identity. To illustrate, a common response to the question ‘who are you?’ is to list the roles that you hold. At this level, the roles are defined by the relationship the individual
has to each role and how the roles interact with other people and their roles. For example, the role of sister does not exist without a sibling or the role of student cannot exist without a teacher. Roles people have access to are influenced by the outer layer of culture and historical context. For example, how the current culture understands and perceives disability as well as the historical view of disability shapes the roles that a person with disability has access to. If historically and culturally, people with disability are perceived as unable to work, a person with a disability may not have access to the role of employee. On an individual level, people use a variety of identity configuration strategies to navigate their various roles and to find ways to occupy new roles.

The third level, found at the center, is where the different roles and domains of individuals interact (Galliher et al., 2017). Current identity research has identified eight identity domains including religion, occupation, politics, values, romance, friendship, family, and gender roles. At this inner level, the process of the development of sense of self occurs as chosen and assigned roles interact with the identity domains. In the model, this creates a shape in the center that resembles one from science that is used to depict the path of electrodes around an atom (Rutherford Model, n.d.). In the center of the intersecting circles is the individual, with the circles representing the many directions and intersections an individual travels in order to make sense of their many roles and domain contexts (Galliher et al., 2017). These interactions bring about many potential combinations of behaviors, experiences, and interactions. Some of these may bring about identity conflict, such as when the social role of “individual with disability” interacts with the domain of “romance.” In the domain of romance, interactions with the role of disability may be influenced by the cultural beliefs that people with disability are asexual. This identity configuration of disability and romance may feel conflictual to the person with a disability, because even though they are perceived as asexual they do not identify as such. Other
situations may result in an identity configuration that feels coherent. For example, when the social role of “individual with disability” interacts with the domain of “politics.” Here the two may interact to create behaviors of activism, which are experienced by the individual with disability as cohesive as their activism behaviors match their existing values. Over time, a person continues to develop, and the configurations of their identity will continue to shift and move towards cohesion.

Lastly, the fourth variable of the model is found outside the concentric three levels, which are the everyday experiences, micro contents, and behaviors of the individual or what the authors refer to as the “lived experiences” (Galliher et al., 2017). The authors describe this level as providing a “phenological” perspective that deepens the understanding of how individuals experience identity. The microcontents are points in time which allow observations of the interactions described above to be collected and analyzed. The microcontents also contain the thoughts, feelings, and behaviors that are associated with an individual’s understanding of their current identity. The authors consider their model as developmental because these levels are interacting continuously throughout the lifespan and thus influencing how identity is developed and understood. As culture and historical context comprises the outer most level of this model, systems of power and privilege are also highlighted as an integral piece of understanding identity development.

*Multilevel model of identity content in context model and the disability experience.* The multiple levels this model provides for understanding identity development makes incorporating the disability experience relatively straightforward. This model describes a series of interactions that start at a large cultural and historical level and then move to identify the various social roles, subscribed and assigned to an individual. It uses the outer layer to help describe the relationship the roles have with each other to develop an understand of the identity configuration an
individual might use to develop their self-understanding. At the inner most level, the model describes how roles interact with identity domains. The microcontents, which sit outside of the concentric rings, allow the individual and others to witness how an individual is configuring their disability into their identity at any given moment in any given relationship with other roles or identity domains. When the role of disability is plugged into this model, it is evident that disability status is a key moderating factor at all levels of identity development process. The developmental nature of this model may also be key in providing a more concise understanding of disability identity development over the lifespan.

**Minority Models of Identity Development**

The term “minority group” comes from the sociological perspective. The sociological definition is “a subordinate group whose members have significantly less control or power over their lives than members of a dominant or majority group have in over theirs” (Schaefer, 2011, p. 245). There are five properties of a minority group. They are unequal treatment, physical or cultural traits, ascribed status, solidarity, and in-group marriage. Originally sociologists used the term “minority group” in reference to ethnic and racial groups such as Chinese, Black, Jews, and Hispanics. However, Sue and Sue (2013) expand the use of the term in their R/CID model to include LGBTQ, women, and people with disabilities, as these groups are often targets of prejudice and discriminatory behaviors. Prejudices refer to the negative attitudes and beliefs majority groups have about the minority group (Schaefer, 2011). Discriminatory behaviors are the actions that come about due to the prejudice. These actions deny people in the minority group equal opportunities and equal rights.

The above understanding of the term “minority group” certainly seems to describe the disability experience. People with disabilities have long suffered unequal treatment even with the enactment of the Rehabilitation Act in 1973 and the Americans with Disabilities Act of 1990
(Sales, 2007). People with disabilities continue to face unequal treatment in a variety of settings. People with disabilities often have some kind of physical trait that sets them apart, sometimes these traits are invisible, such as in a traumatic brain injury, other times they cannot be ignored, such as an amputated limb or the use of a wheelchair. People with disabilities do not choose to be in this minority group, they are regarded as belonging to it. The sense of solidarity is what helped push through the Rehabilitation and Americans with Disabilities Acts. This solidarity is also present on the internet in Facebook groups for people with disabilities, blogs, and on websites. In-group marriage may not be as frequent an occurrence in this minority group, however, this author can easily list several marriages where both individuals have a disability. People with disabilities are also targets of prejudices and discriminatory behaviors including a general lack of accessible parking, the surprise of random strangers when they learn a person with a disability has a successful career, or when having to use the back door because the front is not accessible.

Minority models were first developed following the Civil Rights Act of 1964 to describe the experience of those from specific racial minority groups (Gill & Cross, 2010). Gill and Cross (2010) state that the theories on Black identity began with the need for those who experienced wave two of the Black Social Movement in the form of Black Power. The need for a Black identity theory was originally filled by Cross with his Nigrescence Theory. Over time, Black identity theories prompted others to develop theories to include a wider variety of minority groups. It is these early theories and models that laid the groundwork for researchers to start developing ideas around disability identity development. Since all of these groups do have minority status, there is some overlap in the ideas contained in the models. Though early minority theories or models are not written for disability groups, they certainly planted some seeds in the minds of disability researchers.
Racial identity development. Theories of cultural and ethnic identity development typically describe a process through which an individual moves through stages that allow him or her to have increasingly healthier states of psychological well-being (Mpofu & Harley, 2006). The ultimate goal for the individual is that he or she becomes aware that he or she shares a common heritage with others and moves toward “a highly conscious identification with [his or her] own cultural values, behaviors, beliefs, and traditions” (Chávez & Guido-Dibrito, 1999, p. 41). In general, models of racial and ethnic identity development explain how the individual becomes comfortable in his or her own skin as a member of a minority living within a majority that is racially and ethnically different. Several models of racial identity development are important to highlight as they seem to get more mention in the literature.

Cross. Cross’s model is specific to Black identity development and consists of five stages: pre-encounter, encounter, immersion or emersion, internalization, and internalization-commitment. In the first stage, at least at a subconscious level, the Black person becomes aware that White is the way to be in society and reacts by distancing himself or herself from other Black people. In the encounter stage, a person begins to acknowledge that racism impacts his or her life. In the third stage, immersion or emersion, the Black person tries to emphasize his or her Blackness while avoiding anything that may symbolize Whiteness. In the internalization phase, the Black person is said to become less defensive, maintains connections to his or her Black heritage and networks, and also begins to establish respectful relationships with Whites. In stages four and five, Blackness becomes a positive aspect of the person’s identity. As he or she moves into the final stage, internalization-commitment, he or she begins to explore the construct at a broader and less personal and individual level (Tatum, 1992).

Helms. The model proposed by Helms, which describes how White Americans become aware of racial identity, also consists of five stages: contact, disintegration, reintegration,
pseudo-independence, and autonomy (Helms & Carter, 1991). During stage one, contact, a White individual is unaware of his or her Whiteness as well as any attitudes he or she may carry about Black people. In stage two, disintegration, Whites begin to feel guilty as they become aware of racism and their own past participation in it. This stage leads to the reintegration stage, during which Whites feel hostile towards Blacks and feel strong positive ties to their Whiteness. During the pseudo-independent stage, White individuals begin to have genuine curiosity about Black people and may begin to have relationships with Black people; during this stage, they have become comfortable with their Whiteness. Finally, White people start developing an appreciation of differences and opportunities to learn more about cross-cultural ideas (Tokar & Swanson, 1991).

*Sue and Sue*. Sue and Sue developed the Racial/Cultural Identity Development Model (R/CID) (Salazar & Abrams, 2005; Sue & Sue, 2013). According to Salazar and Abrams (2005), this model has been applied not only to people of various racial groups, but also to other groups who have been oppressed and marginalized, such as LGBTQIA, the female gender, lower social class, and even disability status. They explain that being a member of a marginalized group includes the experience of various forms of oppression, and the interactions of sociopolitical forces, such as the sexism embedded in racism in weight prejudice, and in ableism, and the impact of classism on the experience of gender or sexual orientation. (p. 51)

The R/CID is a developmental model that describes a person’s awareness of self in relation to self, others, and society. It also includes overcoming oppression that has been internalized (Sue & Sue, 2013). Sue and Sue (2013) identified five stages of the R/CID model: conformity, dissonance, resistance and immersion, introspection, and integrative awareness. In the first stage, conformity, the ideas of the majority population are internalized and valued. In
response to the value placed on majority culture, the individual may distance himself or herself from others of their minority culture. The dissonance stage is usually spurred by an event or series of events in which the stereotype of the majority is contradicted by the event(s). This results in the individual beginning to question the truth of stereotypes. In the resistance and immersion stage, the individual often experiences strong emotions and directs them outward. As the energy to sustain strong emotional responses diminishes, the individual moves into the introspection stage, during which energy is used to consider the meaning of self and seek a sense of balance between minority and majority thinking. In the final stage, integrative awareness, the individual is able to achieve a sense of autonomy and security in who he or she is. They have also become accustomed to the sense of ambiguity that is often involved when a person belongs to more than one identity group.

**Application to disability theory.** The concepts contained within ethnic and cultural identity development theories and models seem as though they could be similar to disability identity development. A young person with a congenital disability may not fully realize there is a non-disabled way to do things, they are apt to just accept things the way they are. As they get older, they may begin to realize that their disability makes them different and maybe even tune in to different expectations others have for them. These different expectations and other societal beliefs may become internalized and a process of introspection may ensue. Lastly, a psychologically healthy person with a disability reaches a point where they are able to balance societal views with their own lived experience, taking what they want and leaving the rest.

People with disabilities may very well undergo a similar process as they strive to incorporate their disabilities into who they are. In addition, they like many from minority racial groups, experience discrimination based on their inability to fit into the white able-bodied dominate normative standard. However, these models do not seem to be a perfect fit, as the
discrimination that people with disabilities experience does not come from the same motivations as racial discrimination. Racial discrimination comes from negative assumptions based solely on skin color or possibly foreign accent, whereas disability discrimination is often based on the assumptions that a person with a disability is incapable of doing many or all of the activities a person without a disability is capable of doing, a phenomenon called “spread” (Wright, 1964). It could be presumed then, that since the attitudes behind ableism and racism are different, so are the effects of each. The oppressed groups and individuals in each case would still process and internalize the ablest and racist attitudes but the effects on behaviors would likely be different in order to match inherent expectations of each attitude.

**Models of Disability**

There seems to be some face validity for the application of racial and ethnic identity development theory to disability identity development. However, on closer examination it is insufficient to fully explain the process of disability identity development. What, then, does disability literature say about the process of identity development for those with disabilities? The following sections will review in depth the disability literature as it pertains to identity development. Early models of disability described perspectives through which to view disability rather than describing an identity process. More recently, several scholars have attempted to outline theories of identity development, but these are wrought with problems. Namely, many of them have not been tested, are intended to be applicable to multiple disability types, or have come out of a student’s dissertation without further follow-up.

**Medical model.** Historically, disability has been viewed and understood by means of the medical model of disability, which grew out of the fields of science and medicine (Smart & Smart, 2007). It explains disability as a problem, a pathology that lies within the individual. It assumes that this pathology needs to be corrected and treated and that the individual with
disability is defective. As the problem of disability resides in the individual, so is the responsibility for a solution. According to Smart and Smart (2007), these assumptions remove any sense of responsibility from society as a whole. In addition, they validate stigmas, prejudices, and other forms of oppression against people with disabilities.

Doctors are able to distance themselves from the patient with the use of medical tests and other science-based techniques to diagnose and treat patients with disabilities (Marks, 1999). This distance then limits the doctor’s ability to hear the patient’s expression of what he or she is experiencing. According to Marks (1999), the role of medicine puts doctors in a powerful role that often leaves the person with a disability in the sick role. Her biggest critique of the medical model is the idea that if the disability could be treated successfully, disability could be eliminated. It also assumes that people are either able-bodied or disabled when in reality disability lies along a continuum and is not an either/or category.

**Social model.** The social model views disability as a socially constructed issue. In addition to the biological component of disability, the social model recognizes that societal barriers cause or exacerbate disability (Smart & Smart, 2007). These barriers include peoples’ attitudes, lack of technology, legislation, socioeconomics, politics, and other cultural influences. Theses social factors shape how someone with a disability may react to disability, define disability, and ultimately perceive himself or herself (Vash & Crewe, 2004). In this model, partial responsibility for remediation of the disability lies within society as a whole. It can be remediated through education that works on shifting attitudes through education, by making small changes in the physical environment and providing equal access to services. An example of this is the concept of “Universal Design.” Universal Design is a frame work of architecture and program design that involves developing “environments or tasks to allow for greater accessibility for all people” (Goegan, Radil, & Daniels, 2018, p. 181).
There are many ways that society interacts with disability status that results in the person with a disability being more limited. Marks (1999) noted that the ability to work and contribute to society is one way society shapes disability. Before the advent of industrialization, many people with disabilities could still help on farms and in towns doing simple, less demanding jobs. However, with the rise of industrialization and factory work, many of the widely available jobs became more demanding, and people with disabilities could not compete with able-bodied peers. Another way that society affects disability is through architecture. Disability hostile architecture can exclude people with disabilities in many ways, it can exclude them from a venue that only has stairs and no elevator (physical disability), has poor lighting (visual impairment), or has poor acoustics (sensory integration, Deaf, or hard of hearing). Architecture that has been updated often still marginalizes people with disabilities by not truly making a bathroom stall accessible for people with disabilities or putting the accessible entrances at the back of the building. If these issues were remedied, the person with a disability would no longer be as disabled because he or she would have access to the opportunities that others in society have.

**Minority model of disability.** As noted above, a minority group is “a subordinate group whose members have significantly less control or power over their lives than members of a dominant or majority group have over theirs” (Schaefer, 2011, p. 245). Often when considering minority groups in the United States, one thinks of individuals with a different cultural background, such as African, Asian, or Middle Eastern. One may also consider those of a different religion than the mainstream, such as Muslims. One may even consider how women are a minority group, even though women outnumber men in the population (Schaefer, 2011). However, it seems that thoughts about those with disabilities as a minority group do not come as readily.
If disability is explored through a minority group perspective, the oppression, marginalization, stereotypes, and other risk factors inherent among minority groups also exist for those with disabilities. Erikson once stated that those in a minority group who are constantly oppressed will at some point internalize the oppression (Salazar & Abrams, 2005). Moreover, according to Darling (2013), “stigma is relationship and context specific; it does not reside in the person but in a social context,” (p. 39). As noted by Salazar and Abrams (2005), there is a power differential between those with disabilities and those without disabilities. Within this differential, those with disabilities have the seat of less power while those without disabilities have more power. Therefore, like other minority groups, those with a disability are at higher risk than their non-disabled peers of being abused, harmed, and taken advantage of by those with the power. Due to the stigma, the seat of less power, and the negative attitudes associated with minority status, it is not a particularly healthy place from which to draw information about the self when developing an identity.

**Development of Disability Theory**

As of 2006, no widespread theory of disability identity development was available (Mpofu & Harley, 2006), though some scholars have made attempts. Gill (1997) proposed an integration model of disability identity that describes how an individual with a disability develops an integrated identity. Additionally, a dual-process model of disability identity emerged from a 2004 dissertation by Weeber, a doctoral student at North Carolina State University (Weeber, 2004; Leung, 2011). These models are a start but are not in themselves sufficient due to their many limitations. The following paragraphs will describe and critique these models.

**Gill.** In 1997, Gill published an article titled “Four Types of Integration in Disability Identity Development.” Noting that integration is a common theme among many theories of personality development, Gill views the goal of identity development as an integration of
individual and group levels of identity. “Dr. Gill proudly identifies as a woman with a disability” (National Forum on Careers in the Arts for People with Disabilities) as such she uses the first person to describe the four stages of her model which consists of: coming to feel we belong (integrating into society), coming home (integrating with the disability community), coming together (internally integrating our sameness and differentness), and coming out (integrating how we feel with how we represent ourselves). As the individual progress through these stages, he or she gains a greater sense of identity integration. In coming to feel he or she belongs, the individual is seeking a social role as a person with a disability and is able to assert that they have rights. In stage two, coming home, the individual stops avoiding others with disabilities and starts interacting with the disability community. In the coming together stage, the individual is seeking psychological wholeness as a state of having some disabled parts and some non-disabled parts. This stage can be confusing and may produce a sense of a disintegrated identity. To become psychologically whole, the individual must be able to reject the messages he or she has received from society and take pride in all he or she is. Finally, in the coming out stage, the individual becomes comfortable enough in his or her own skin that his or her internal sense of identity matches his or her external presentation in society. Each of Gill’s four integration stages describes a part of the path of disability development (Darling, 2013). This journey begins with wanting to find a place of belonging in society and finishes as the person continues to develop into a person who accepts himself or herself as complete.

**Weeber.** In 2004, Weeber published her dissertation entitled *Disability Community Leaders’ Disability Identity Development: A Journey of Integration and Expansion*, in which she proposes a model of disability identity development. Weeber (2004) described her model as a “dual-dimensional process” (p. Abstract). The first process is positively integrating disability into the self and the self into the community. The second process is the growth of the disability
experience to include the understanding that disability is diverse, disability has social and goal aspects, and people with disabilities are still part of humanity as a whole. She used a mixed qualitative method which utilized ethnographic and phenomenological research methods. Using these methods, she then conducted in-depth interviews of “leaders of the disability community” (p. 69) with “positive disability identity” (p. 70).

The following is a summary of Weeber’s six positions. In the first position, people with disabilities encounter people without disabilities who are seen as being superior; thus, the person with a disability tries to adopt a non-disabled identity. In position two, the disability experience takes on new meaning as the individual begins to connect with the disability community. In position three, the person sees the disability experience as including oppression and discrimination. Position four is about seeing the place the disability community occupies in the world. In position five, those with disabilities begin to understand a common link between themselves and other minority groups. Finally, position six is one of transcendentalism, where the person is able to see the connectedness of all humanity, disabled or not (Leung, 2011).

**Critique of models of disability and disability theory.** All of the models of disability fall short due to their narrow lens, which misses the big picture. Disability does not fall neatly into any one of these categories. It is not just a medical, social, or minority group status issue. Rather, it is an intersection of these and other group memberships such as race, religion, and socioeconomic status. Congenital conditions are medically-based, as they have roots in biology, which can often be treated through the practice of medicine. Each condition also has received its name through medical science, and much of the research on etiology of congenital disabilities has been done through medical research. However, on a daily basis, disability is frequently experienced as a social construct, as people with disabilities interact with the world on a daily basis. Often, the attitudes, facilities, and other environmental factors affect a person’s life more
than the medical factors. The minority model also has a one-dimensional description of
disability, as it only focuses on disability status. This in its very essence adds to the “less than”
value a person with a disability may already experience. Though each of these models has value,
one adequately describes the disability experience.

The face value of the theories on disability identity development seems high. Both have
done a decent job of outlining the steps the authors observed in the data they collected. However,
neither model is without its downfalls. First, both use multiple disability types within their
samples. Some of the disabilities they listed in their research include birth defects, acquired
disabilities, deafness, blindness, polio, post-polio, and cognitive disabilities. Gill (1997) also
used observations of “allies of those with disabilities” (p. 41) to formulate her integration theory.
In her dissertation, Weeber (2004) offered the following as her reason for not focusing on just
one disability group; “Because the disability community identifies itself as cross-disability in
nature, ‘diversity’ within the context of disability studies scholarship, such as this study, must
also include the diversity of types of disabilities” (p. 69). Weeber also used “leaders in the
disability groups” as her interviewees, she must then, be assuming that those leaders have
healthy self-identities, which may not have been the case. Lastly, Gill’s theory goes as far as
suggesting that an individual with a disability is not psychologically whole and acceptable until
he or she has gone through the whole process. The incorporation of all disability groups and
implying that a person with a disability is not whole psychologically until he or she fully
integrates into society assumes that being fully integrated into society is the purpose of identity
development. Identity development is about gaining a knowledge and understanding about the
self, not about the level of societal integration.

Models of disability are too narrow while the existing theories of disability identity
development are too broad. Disability is multifaceted, can be described from a multitude of
perspectives, and it effects every part of a person’s life. Models of disability fall short in that they describe a person’s life from only one perspective leaving other facets untouched. Existing theories of disability attempt to describe the process of identity development as being the same across disability types. These descriptions are then erroneous because how can the experience of a person who cannot walk be the same as someone who is Deaf and belongs to the Community? Or how can the experience of someone with Cerebral Palsy who has an IQ of over 140 but cannot communicate be the same as that of someone with Down’s Syndrome who has an IQ of 60 but can speak and communicate? It is this author’s belief that these experiences cannot not be described by one theory and that the process of identity development across different disability types must be separated out. The goal of this present study is to do just that. By identifying themes across studies regarding disability identity development for people born with congenital physical disabilities, the groundwork will be laid for the future development of a sound theory on identity development for this population.

**Limitations to disability research.** There are many limitations to studying and researching disability issues. One of the limitations of Disability Studies research in general is that most studies have a small number of participants (Darling, 2013). In addition, Darling (2013) also critiques disability identity research specifically because it does not address the processes that occur as identity and orientations are created or developed. Additionally, the multiple minority statuses of many with disabilities is generally absent in the research. Darling (2013) discusses the salience of identity, conflicting goals of identities, and how the interplay of the conflicting goals and role salience may lead to greater stigmatization. Internal conflict arises when a person belongs to two or more identity groups that do not have the same goals (Mpofu & Harley, 2006), thus potentially causing more conflict for those with disabilities. Though this may sound repetitive, a final limitation of much of the disability identity research is that it is done
with heterogeneous groups of people with disabilities. It does not make sense to study cultural and ethnic difference by using participants of varying backgrounds, yet this is how most disability research has been conducted. It is hoped that the results of this dissertation will take into account the aforementioned limitations and thus will intentionally take steps to ensure that they do not interfere with the data collected.

**Conclusion**

In the widespread scholarly discussion of identity, disability identity development has been largely forgotten. Early theorists omitted it completely, whereas more recent theories include it only in as much as it is a minority status or part of a social influence. Scholars who have considered how a disability identity forms have done so by looking at heterogeneous disability groups. Combining multiple disability types is analogous to combining all ethnic minorities into one group: an atrocity that would rarely be committed now. It is beyond time to start furthering the psychology of disability and identity and asking how processes differ among disability groups. It is the hope of this current study to weave together the current data to lay a foundation for the development of disability identity theory specifically for people who have congenital physical disabilities.
METHODOLOGY

What is Phenomenology?

The specific method used for this study was the phenomenological method proposed by Giorgi (2009). The aim is to describe the phenomenon of identity development for individuals with the disability spina bifida. The main goal of phenomenology is to take a natural standpoint, in which one is a witness making observations of the entity under study in order to describe (rather than explain) the phenomena of interest (Sadala & Adorno, 2002). The researcher makes deliberate attempts to not use past knowledge to account for themes (Giorgi, 2012), Rather, as Giorgi (2012) explains, the phenomenon is described exactly as it occurs.

Phenomenology originated in the works of Edmund Husserl (Wertz, 2005) with his desire to return research focus to the lived experience of the individual, rather than observation by the researcher (Sadala & Adorno, 2002). Husserl outlined two procedural epochès, Natural Science and natural attitude, or ways to bracket and abstain from using previously known information (Wertz, 2005). In the Natural Science epochè, the researcher puts aside all “natural scientific theories, explanations, hypothesis, and conceptualizations” (p. 168). In the second epochès, Natural Attitude, the researcher puts aside or brackets any previous personal experiential knowledge of the entity under study. Natural Attitude allows researchers to reflect purely on how the entity presents itself in the “life-world” or “lebenswelt” the German word Husserl used (Wertz, 2005). By doing their best to follow these procedural epochès, the researcher attempts to describe the entity as close to exactly how it appears in the world.

Once prior knowledge of the entity has been set aside with a process known as bracketing, the researcher can commence with the psychological phenomenological reduction. This process takes the entity under study and describes it by reducing it to its parts, meanings, and psychological behaviors (Wertz, 2005). Per Wertz (2005), this process has several functions.
First, it allows the researcher to describe and clarify the characteristics of the entity. Finally, it describes and brings into light the structure of the phenomenon under study.

Once the researcher has reduced the entity to its basic parts, known as meaning units, the task of free imaginative variation is carried out. During this task, the researcher examines each part from a multitude of angles and perspectives to discern whether or not it is an essential part of the phenomenon under study. Those parts that are deemed “unessential” are discarded, while those deemed “essential” become part of the final description offered by the researcher.

Giorgi

Giorgi’s (2012) phenomenological method proposes five steps to the phenomenological method of bracketing, reducing, and describing, as listed subsequently. In step one, the researcher first reads the whole description in order to get a sense of the whole or the “big picture” of the idea being communicated. In the case of this study, published studies describing identity development as it pertains to people born with the physical disability of spina bifida have been collected and will serve as participant’s verbatim transcripts. In the first reading, the researcher did not analyze any of the content, rather she read with the goal of achieving a sense of the process of identity development as it pertains to people born with spina bifida in its entirety. Sadala and Adorno (2002) describe this process as experiencing the gestalt or the wholeness of the phenomenon.

In step two, the researcher went back to the beginning of each article to re-read it, but this time she began to analyze the content. In most cases, this is a transcript of a qualitative interview; since in this present study, published articles are being used in lieu of participants, “description/s” is a more accurate term. As she reads the descriptions, the researcher marked when they experience a transition in the description. Here the researcher will be looking for the different ways identity development is described and experienced. Every time she notices a shift
in the meaning, however small, she makes a mark on the page, this is a process called “constituting parts” (Giorgi, 2012, p. 5). This step results in a variety of marked clusters of meaning which are called “meaning units” (Giorgi, 2012, p. 5) and are subjective to the researcher. Meaning units are the beginning of developing themes across the literature.

In step three, the researcher transforms the data into psychological constructs by relating the raw data to the phenomenon being studied. More simply stated, the meaning units are studied and further dissected in order to identify psychological concepts that are pertinent to the phenomenon of identity development as it pertains to people born with spina bifida. At this point the descriptive phenomenological technique of Free Imaginative Variation is used. Free Imaginative Variation is essentially a thought exercise in which the researcher imagines each meaning unit independently of the others and asks about its pertinence and necessity to the phenomenon. This is the “heart of the method” (Giorgi, 2009, p. 130) as here is where two things happened. First, the researcher translated the meaning units into phrases or themes that highlight the psychological processes of the phenomenon under study (Giorgi, 2009, 2012). Second, the method of Free Imaginative Variation was used to determine if the meaning unit is an essential part of the phenomenon under study. In other words, if it were not included in the description, would the phenomenon still exist? If the answer is “no” then the meaning unit is deemed “essential.”

This is a crucial step to understand as this is where the key components of the process of identity development as it pertains to people born with spina bifida were identified. To determine if a meaning unit or a psychological theme is essential the researcher, using Free Imaginative Variation, isolates one meaning unit at a time, imagines that it is independent of the others and what the phenomenon would be if it were left out of the description. Doing this allows the researcher to determine if the basic structure of the phenomenon is at all altered by the removal
of the specific unit. If not, that particular meaning unit is deemed non-essential. However, if the phenomenon is not the same, if it changes, without the unit, it is deemed essential (Giorgi, 2009). Giorgi (2012) refers to this step as “the heart of the method” (p. 6). At the completion of this step, the researcher highlighted the psychological meanings, which then allows a greater psychological generalizability and more easily allows for integration of the parts in step four (Giorgi, 2009).

In step four, the psychological meanings of identity development as it pertains to people born with spina bifida were reviewed and integrated. The researcher first reviews the psychological meanings identified in step three, then begins to sort them into groups based on their similarities. During this step, themes of identity development for people born with physical disabilities begin to develop. The use of Free Imaginative Variation was continued so as to determine the essential nature of each psychological meaning in the context of the greater group. In this study, the psychological meanings were questioned as to their pertinence to the essentialness of the developing themes of identity development as it pertains to people born with spina bifida. The themes were also questioned as to their essentialness to the description of identity development as it pertains to people born with spina bifida. As the researcher did this, the essential structure of the phenomenon began to develop and was written down. At the end of step four, the researcher had a complete description of the essential structure of the phenomenon as well as the themes and psychological meanings that were deemed non-essential.

In step five, the last step, the essential structure was used to help clarify and interpret the raw data and non-essential elements of the data (Giorgi, 2012, pp. 5-6). The researcher uses the essential structure to clarify and interpret the raw and non-essential data of the research, as it can describe the context in which the essential structure exits. In describing the context and other non-essential variables of identity development as it pertains to people born with spina bifida, the
researcher is providing a second-order psychological description of the phenomenon (Giorgi, 2012). Step five allows for a fuller understanding of the phenomenon, which provides a sense of unity throughout the data set (Giorgi, 2009).

**Phenomenology and the Present Study**

The goal of this study was to develop a description of the process of identity development as it pertains to people born with spina bifida. Thus, Phenomenology was chosen as it outlines a process that was utilized to describe a given phenomenon, in this case, identity development. Eventually, it would be ideal to develop a cohesive theory of identity development for each disability type (e.g., visual impairment, congenital physical disabilities, acquired disabilities, cognitive disabilities,). However, at this time, there is not enough specific data to make such an extravagant proposal. Much of the data available uses a mixed disability population sample, differing methodologies, and variations of definitions of terms, making the development of any one theory difficult. Those theories that do exist are wrought with problems, as many include multiple disability groups making generalizability almost impossible. That said, there are many small pockets of research data available that seem to have some common characteristics and themes.

**Study purpose.** The present study aimed to filter commonalities in an effort to set the stage for theory development in the future. Originally the phenomenon of “identity development for people with congenital physical disabilities” was to be examined as it appears in a variety of literature. However, as data collection proceeded into steps two and three, it became evident that there were not enough available resources on many congenital physical disabilities, therefore the phenomenon being studied narrowed to “identity development for people with spina bifida.” the sources included research articles, books, videos, and other available sources (e.g.: websites). These sources were be used in lieu of human participants as this study aimed to explore
constructs not already named or identified through previous studies. The goal of this study is to sort through pertinent sources of data, extract common themes, and formulate overreaching themes and to more fully explore disability identity formation.

**Data collection.** Much of the literature collected was the result of multi-database searches via the Antioch Seattle library. The databases used include PsychInfo, Medline, PubMed, Psychology and Behavioral Sciences, and ProQuest. We Deliver was also used to procure documents not readily available. Key word search terms included “physical disability AND identity development,” “ethnic AND cultural identity development,” “identity development,” “theories of identity development,” “models of disability,” “spina bifida AND identity development.” These searches resulted in hundreds of peer reviewed journal articles, dissertations, books, and book chapters. The researcher shortened the search result lists by excluding articles that were not specifically tied to the search criteria or were only available in a foreign language. Other examples of reasons for exclusion include: articles that discussed physical disability occurring because of aging or acquired injury, studies that did not use participants with physical disabilities, and studies that used mixed-disability group subjects. Additional sources were identified through the citations listed in the documents found. Several books and book chapters were found by looking at the “suggested for you based on your purchase” recommendations on Amazon.com, which is based off of previous purchases of a variety of books and items. As needed, the internet-based search engine Google was used to search for hard to find references suggested through the aforementioned methods.

**Meaning units.** The methodological steps suggested by Giorgi (2009, 2012) have been used for this project. This researcher used Sente 6 and NVivo software to store digital copies of sources and to track meaning units. Articles were organized under general categories such as “health,” “psychosocial,” “transition,” and each category was then taken through steps 1-3 of the
process, which was repeated with each group until all data sources had been reviewed and data compiled. Initially, 139 articles were chosen for inclusion into this thematic analysis.

All articles were uploaded to Sente 6 which was used to complete steps one and two of the phenomenological process. Step one was a thorough read through so that this researcher could get a sense of the gestalt. During this read, no notes were taken and nothing was highlighted the researcher simply became aquatinted with the literature. This thorough read through led to 28 articles being excluded for lack of applicability; typically they addressed disability too broadly to be applied specifically to issues of identity development. During step two, 111 articles were re-read. This time, as the articles were read, the researcher highlighted sections that seemed important and made memos of thoughts and questions she had while reading. It was during this step that this researcher realized that most of the articles she was reading pertained only to people with spina bifida. of the 111 articles, only twelve pertained specifically to cerebral palsy and one to congenital limb malformation. This led the researcher to decide to narrow the boundaries of the phenomenon under study to “identity development for people with spina bifida.” These 13 studies plus another 19 that under closer examination did not fully meet research criteria were excluded.

The last step in discovering meaning units was completed in NVivo, software designed to help organize and analyze qualitative data sets. The remaining 79 articles were uploaded to the program and sorted back into their categories, which NVivo refers to as parent nodes. The articles were again re-read and this time meaning units were coded into smaller inter-related units. For example, under the parent node of “health,” child nodes were coded as “mental health” and “physical health.” This process resulted in 9 distinct themes related to identity development for people with spina bifida.
Describing the phenomenon. In steps four and five of Giorgi’s (2009, 2012) methodology, the researcher began to write findings. The researcher applied Free Imaginative Variation to the psychologically focused terms, again trying to clarify which terms are part of the essential structure of identity development, and which are extraneous descriptions. The statements were then combined in a way that described the true nature, characteristic, and structure of the phenomenon. Lastly, the concise description was used to review the raw data collected in step two. Even though the raw data may not be essential, it may help to add detail and explanations to the essential structure of identity development.

Throughout the entire process, this researcher also used the qualitative technique of memoing from grounded theory. This was performed for several reasons. First, it allowed for the tracing of thoughts, ideas, and opinions. Some of these were valid for data exploration, while others needed to be bracketed and set aside. Memoing also helped identify early connections as they occurred, preventing them from disappearing within the magnitude of the final database. Lastly, it helped this researcher more easily keep track of progress as it was made.
RESULTS

Identity Themes

By analyzing 79 articles using Giorgi’s (2012) Descriptive Phenomenological methodology, nine essential themes of identity development emerged. These nine themes occurred at every level of the Multilevel Model of Identity Content in Context model. As with the components of the model, the themes are interrelated, changing over time. None of the themes are more or less important; each are equally influential in the process of identity development. The following are the nine themes described in more detail. See Appendix E Table 1 and Figure for visuals of results.

Impact of Others

There are many societal myths, stereotypes, and beliefs about people with disability expressed in many covert and overt ways. People with spina bifida often live in direct opposition to the myths, as they live lives that demonstrate their inaccuracy. However, this does not mean they are not affected by the myths about them. Indeed, opportunities are not as available to people with SB due to the misinformation perpetuated from these myths, and can contribute to internalizing disorders such as anxiety. The resulting loss of opportunity and increase in mental health issues tends to impact one’s sense of identity. This theme was coded 43 times across 10 articles.

View and Understanding of Disability

This theme is about how an individual with spina bifida perceives, describes, and labels the disability. It also includes how an individual understands and assigns meaning to their disability. It specifically addresses how an individual with SB has incorporated their disability status into how they perceive themselves. In comparison to other themes, this theme was
identified the fewest number of times despite being closely tied to identity. This theme was coded 36 times over 11 articles.

**Employment**

People often define themselves by their jobs. When asked who they are or what they do, responses tend to focus on employment, as it has become an essential piece of identity. People with spina bifida often want to work but struggle to find adequate employment and are often unemployed or underemployed. The lack of employment affects how they think of themselves and who they are. It also limits roles they can achieve and integrate into their identity. The theme of *Employment* occurred 65 times across 16 articles.

**Psychological and Mental Health**

Research is conflicting on whether people with spina bifida are at greater risk for mental health issues such as depression, anxiety, or poor adjustment (Bellin, et al., 2010; DiCianno et al. 2015; Hayter & Dorstyn, 2013; Soe, Swanson, Bolen, Thibadeau, & Johnson, 2012). Often though, research suggests there is a higher prevalence of these issues in populations with spina bifida than the general population. In addition, there is certainly a greater risk for the development of issues with low self-esteem, negative body image, and poor self-perception. The theme of *Psychological and Mental Health* was coded 249 times across 37 articles.

**Physical Health**

Often times youth with spina bifida need medical intervention to treat and prevent physical health issues. Indeed, through childhood and into adolescence and adulthood, secondary health issue such as urinary tract infections (UTIs), pressure sores, and orthopedic issues cause physical health concerns and the need for medical intervention (Hunt & Oakeshott, 2004; Liptak et al., 2015). These ongoing issues can derail an individual’s sense of self and contribute to an
unhealthy viewpoint. Physical health status also influences the social roles an individual can attain. The theme of physical health was coded 137 times across 17 articles.

**Family System**

Spina bifida is not just an individual disability, but one that can have an impact on the family system. Taking care of a child with SB can be stressful, financially costly, and time intensive. Thus, it can change the dynamics of a family. These stressors influence family functioning; therefore influencing the identity development of the child with SB. This theme also includes how a child with spina bifida is raised as parenting style fosters a variety of potential outcomes. How a parent interacts with their child may foster a sense of medical fragility, independence, or dependence. Thus, family influences set the trajectory for identity development from a young age. The theme of Family System was coded for 212 times across 31 articles.

**Transition**

Transition refers to the period of time in which adolescent youth are moving towards young adulthood. During this time period, a youth individuates from their parents and begins to develop their own identity (Ridosh, Braun, Roux, Bellin, & Sawin, 2011). Youth with spina bifida often experience this transition period differently than their able-bodied peers, as they are often on a slower transition trajectory. This can make the teenage years more complicated to navigate for youth with spina bifida, and influences how they think of themselves and their disability. This theme was coded 161 times across 25 articles.

**Sexuality**

As people transition into young adulthood, their sexuality becomes a part of their identity. Those with spina bifida are no less sexual than those without SB, but they often experience sexual dysfunction. This dysfunction can lead to a skewed sense of body image and attractiveness. They also run up against myths about the sexuality of people with disabilities,
such as the myth that people with disabilities are asexual. Combined, these two elements are highly influential to the process of a person with SB forming a sexual identity. The theme of *Sexuality* was coded 125 times across 20 articles.

**Psychosocial**

Psychosocial ramifications of spina bifida exist when elements of the individual interact with elements of the social environment. This is a broad theme describing how well connected the individual with disability is to others and to their community. As it describes the relationship between the individual and their social environment, components of this theme can be seen intertwined throughout the other themes. The theme of *psychosocial* was coded 216 times across 40 articles.

The identity constructs presented were highlighted in these research findings, however, the list should not be considered exhaustive. Other important identity content areas include: ethnicity, religion, gender, and sexual orientation.
DISCUSSION

In this section, the themes of identity development discovered during this thematic analysis will be explained in greater detail. Similar to the Multilevel Model of Identity Content in Context model proposed by Galliher et al. (2017), the content of the different themes interact, influencing each other on a daily—and even moment-to-moment—basis, with each interaction giving the individual an opportunity to reconfigure their identity in ways that allow them to experience themselves as coherent in every given moment. For example, the psychosocial theme was one of the most frequently coded themes and is strongly connected to every other theme as it describes the impact of how elements of the individual interact with elements of the social environment. The consequences of each interaction can have varying effects. Sometimes, the consequences provide feedback that confirms the identity of the individual. For example, lack of access to a building or facility may confirm the “disabled” identity. Other times, the new information the interactions contribute provides the individual opportunity to reconfigure their identity. For example, success at a job may cause the identity of the individual to shift, as they become more confident in themselves and their ability to contribute in the work place. There is still much to discover about how identity forms and how disability status influences the process. However, the themes explored below begin to shed some light and provide a foundation on which to build further research. To see how each of the themes fits within the Multilevel Model of Identity Content in Context model refer to Appendix D.

Impact of Others: Societal and Political

Applying the Multilevel Model of Identity Content in Context model, the impact of others includes the outermost level, as well as, the roles level. The impact of others is located in the outermost arena because it includes the general beliefs of the broad social context about disability, often these beliefs are heavily influenced by abilistic ideas. It is the beliefs of the
society about disability that dictate which roles are available to those with disability, in this case the focus is specifically on how these beliefs impact those with SB. The impact that others have on the development of identity for people with SB is important to address, since it is the social world that determines the options and alternatives available to people with disabilities. Put more plainly, the attitudes and beliefs about disability that are held by non-disabled individuals are what dictate the options available to those with disability (Brislin, 2008). Because physical disability is still extremely stigmatized in U.S. culture (Kinavey, 2006), negative attitudes and the behaviors they drive have the potential to limit the opportunities for people with SB to access in school, employment, and social settings. They are also potentially detrimental to the inter psyche of the individual with SB. When these negative views and attitudes are internalized, the individual begins to see themselves through the negative lens, then believes that they are valued less than those without disability. People with SB are exposed to these attitudes in a variety of ways, ranging from the lack of role models in the media to portrayals of people with disability as scary, pitiful, and helpless. Other signs of oppression come via inaccessibility of physical spaces and the ostracization people with SB often experience in social groups (Kinavey, 2006).

Ableism

People with disability group status are the largest minority group in the United States (Strike et al., 2004). Feelings of oppression (Sales, 2000) and a sense of disenfranchisement and exclusion from society (Heinemann, 1993) are common among minority groups, including those with disability. Van Daalen-Smith (2006) found that women who have SB often felt socially marginalized, disempowered, and devalued. Participants also reported running up against barriers to healthcare and other activities that would improve their quality of life. The predominant reason Van Daalen-Smith cited for this was ableism. Ableism is defined as:
the pervasive system of discrimination and exclusion that oppresses people who have mental, emotional and physical disabilities. Deeply rooted beliefs about health, productivity, beauty and the value of human life, perpetuated by the public and private media, combine to create an environment that is often hostile to those whose physical, emotional, cognitive or sensory abilities fall outside the scope of what is currently defined as socially acceptable. Ableism or disability oppression reflects the viewpoint that people with disabilities or limitations are considered to be inadequate in meeting expected social and economic roles. (p. 263)

Ableism is the cause of myriad of daily microaggressions. The marginalization of people with SB is rooted in ableism (Van Daalen-Smith, 2006). For people with SB, their disability often is the only aspect of their identity that others see, which removes from them their dignity, power, and the respect of others (Van Daalen-Smith, 2006). Rembis (2009) writes:

[People] consider disabled people to be not only broken or damaged, but also incompetent, impotent, undesirable, or asexual. Their inability to perform gender and sexuality in a way that meets dominant societal expectations is seen as an intrinsic limitation, an ‘unfortunate’ but unavoidable consequence of inhabiting a disabled body. (p. 51)

In the United States, legislation to help combat ableism has been implemented over the last several decades by guaranteeing access to education, public spaces and buildings, public transportation, and employment to people with disabilities. Often, however, the outcomes of legislation cause those with disabilities to feel more alienated. For example, the mainstreaming mandated by some legislation requires the inclusion of students with SB in typical classrooms. This inclusion effort was intended to make children with SB and other disabilities feel more included. However, the downside to mainstreaming is that the child may be the only one in the
class with SB, exasperating feelings of isolation. One adolescent had this to say about moving from a special education program to a mainstream education:

I don’t really remember much, except to say that, I had friends, a lot, a lot of friends, people that actually, you know, I guess since they were all in the same boat, really cared and understood. And, I went from the situation where every everyone was basically in the same boat, to the situation where I was kind of different. (Kinavey, 2007, p. 156)

Another high school student with SB who had difficulty walking was marked as tardy repeatedly. “I couldn’t climb the stairs very fast and they didn’t understand it… I’d walk the stairs and I’d be late. The teacher would always say: ‘You’re late. Why are you late?’ I’d always have to explain… they’d still mark me late” (Van Daalen-Smith, 2006, p. 267).

**Stigma**

Children with SB may also get bullied at school and be excluded from a variety of activities. One child reported the following: “I was very unpopular, back then, and, when lunchtime would come, I would walk out to the lunch tables outside and they’d say ‘Oh, here comes ‘It’. So I was the boy called ‘It’” (Kinavey, 2007, p. 154). These kinds of bullying experiences, in addition to the social isolation that comes with the experience of “otherness,” emphasizes the sense of marginalization for youth with SB.

People with SB are often quite aware of the stigma associated with having a disability. They notice the stares they get out in public and make comments such as “If only people would not stare at me so much,” or “People only see my disability and not me as an individual” (Börjeson & Lagergren, 1990, p. 701). They are also reminded of their disability status regularly when confronted by activities they are unable to do, which reminds them of their own limitations (Börjeson & Lagergren, 1990). One teen commented, “It’s really hard being a teenager with spina bifida, like getting around and in certain places with certain people looking at you and
saying, well, she’s not right because she’s in that wheelchair,” while another shared the following: “I don’t want to be treated like I’m in a wheelchair. I want to be treated like I’m a person” (Lindsay, 2014, p. 1302). These sentiments can lead to a sense of social isolation, which in turn can cause depression. Worrying about how they may be perceived in public can also lead to feelings of anxiety. Some people with SB may even feel hesitant to associate with others who have disability, because they are worried that doing so will “contaminate” themselves and they will be seen as more disabled (Kinavey, 2007). This is illustrated in a comment from a young adult with SB: “Because of the shame and the stigma that is associated with being disabled, I didn’t want to get into a group of disabled friends” (Lindsay, 2014, p. 1302).

Children with SB are exposed to exclusion and negative attitudes early on in life. They are often excluded from typical recess and park play because playgrounds in these areas are often filled with sand or woodchips through which a wheelchair cannot navigate. “I go to the playground. I just sit there and watch everybody else play” (Lindsay, 2014, p. 1302). Thus, their ability to play with their peers is limited and so is their ability to make friends with TD youth (Bloemen et al., 2015).

Bloemen et al. (2015) note that the protective attitude of adults towards children with SB is limiting. This is in part due to the belief held by the adult in the concept of disability spread, which is the assumption that because a person has one specific disability they are disabled in other ways and must need extra protections to be safe (Wright, 1983). A youth in the Bloemen et al. (2015) study commented on this, stating “they easily think that activities are too hard….if I for example say ‘I want to do this and that’ he will say ‘that is too hard for you….what if something happens….’….well. It is difficult to say otherwise…” (p. 7). These attitudes, though often well-intentioned, place external limits on what children with SB can and cannot do and often teach children from a young age that they are more disabled and limited than they truly are.
Another limiting habit is the behavior of speaking down to youth and even adults with SB and infantilizing them by treating them as if they are incapable, fragile, and vulnerable (Bloemen et al., 2015; Lindsay, 2014). Talking down to a person with SB disempowers them again, often leaving them without a voice and reinforcing abilistic ideals.

**View and Understanding of Disability**

How those with SB view and understand their disability is tightly associated with how society perceives them and how society influences their own perceptions of self. How one views and understands their own disability status is essential to disability identity and is at the very center of the Multilevel Model of Identity Content in Context model. This view of disability is related to, but different from, how one understands or makes meaning out of one’s own disability.

**View of Disability**

An individual can view their SB status in a positive light, as a negative aspect, or avoid it all together. Those who tend to view their disability status negatively are often highly influenced by cultural and societal norms. They may compare themselves to their peer group and rate themselves as inferior and looked down upon (Kinavey, 2006, 2007). They may consider their body as less than perfect when compared to society’s ideal of beauty and bodily perfection (Kinavey, 2007). One young adult who held a negative view of her disability commented, “There was a point in my life where I did not accept the fact that I was disabled. I hated being disabled. I hated not being able to go to dances. I just hated the chair” (Kinavey, 2007). Those with SB may also understand their disability as placing limitations on what they can and cannot do and focus more on what they are not able to do (Lindsay, 2014). This quote illustrates how the individual felt she could not go to school dances due to her disability and use of a wheelchair. An individual may view using a wheelchair or other walking device as a weakness (Kinavey, 2006; Lindsay,
2014). In some cases, such as in the quote above, individuals with SB wish they had been born without a disability (Lindsay, 2014).

On the opposite side of the spectrum are those who view their disability positively. Buran, Sawin, Brei, and Fastenau (2004) found that a majority of adolescents held positive attitudes about their disability status. The youth in their study were confident in their communication abilities, felt hopeful about the future, and had positive expectations for themselves. The study by Lindsay (2014) found that youth with SB reported that they felt positively toward their SB-related status and that they were a stronger individual for it. One participant was quoted as saying, “I think you build your strength as you go. You become tougher each day. You realize you can do certain things that no one else thinks you can” (Ridosh et al., 2011, p. 871). Youth who held more positive views of their disability commented that the support of their family, as well as their religious faith-base, were important factors in helping them accept their disability (Ridosh et al., 2011). Quotes in the literature relating to this include, “I just believe in myself and give the rest to God” (Ridosh et al., 2011, p. 871), and

It’s no one’s fault I have spina bifida. It just happens. I have friends who have diabetes, have been in car accidents. Life isn’t easy for them all the time either. My family has always been there for me. I believe I can accomplish most things. I might have to make an adjustment here and there but most things I can do. I go to church and I know this helps my family too. (Ridosh et al., 2011, p. 871)

A third way to view disability is to avoid viewing it as much of anything. Kinavey (2007) found that many with SB try not to think about it and see it simply as a difference in a society where everyone is different. She gathered quotes such as, “Well, dealing with my disability . . . I don’t think about it much, right now . . . I try to keep it, you know, pretty much out of my life or out of relations with other people” (p. 1100) and “I just try not to view it as being different as
being disabled . . . just being different as everyone is different” (p. 1100). In another article, Kinavey (2006) shares the story of a person who had been avoiding her disability status until she saw another with a similar presentation. This individual described seeing someone else with such a similar instance of SB: “It scared me. It made me feel uncomfortable, you know... It made me more aware of who I was, and so in a way, like, I was running from that” (Kinavey, 2006, p. 1098). In this instance, seeing another with a similar presentation of spina bifida put the object of avoidance at the forefront of her conscious mind. If one ignores one’s disability status and avoids others with SB, one’s sense of isolation and differentness may deepen, which in turn can increase one’s risk of developing mental health issues such as depression.

**Understanding of Disability**

How people with SB understand and make meaning out of their disability status is covered in the work of Kinavey (2006), who sought to understand exploratory models of self-understanding in adolescents with disability. Kinavey was interested in learning how those with SB attached meaning in relation to themselves, the world, and others. To do this, she conducted qualitative research consisting of 43 hours of interviews with 11 participants. Her analysis found that people with SB tended to understand their disability in one of three ways: (a) they developed an identity that saw themselves as overcoming disability, (b) objectifying disability, or (c) integrating disability. In the overcoming disability model, the physical limitations of disability were minimized and tended to be sources of inspiration for others without disability. Individuals in this group had internalized society’s negative views toward disability; therefore, people with this understanding were more likely to compare themselves to others with disabilities who might have been more disabled than they were. A quote Kinavey obtained that speaks to minimizing disability was: “I don’t like to always say that I’m hurting or anything. ‘Cause then I feel like even more looked down upon” (p. 1097). This same person had internalized societal views on
disability. Thus, whenever she was in a romantic relationship with a male, she said she would be thinking, “I’ll still be questioning, like…well why the heck do you want to, like…be with me?” (p. 1098).

If an individual objectified their disability, it was externalized and seen as separate from their self. Individuals with this framework of understanding often felt different from their peers, as if their disability status set them apart. They might have to often explain away disability as just one of a number of differences, such as “everyone has differences,” thereby negating the impact of disability. A quote from the Kinavey’s study captures this: “It’s difficult. It’s actually near impossible, ’cause I know I am disabled and it’s clearly evident (long pause) . . . I just try not to view it as being different as being disabled . . . just being different as everyone is different . . . treating it more as, you know, a difference like a person is male or female, Black or White” (p. 1100). This participant did not consider his view of disability to relate to his depression, experience of isolation, and other life experiences. He saw these as experiences distinct and separate from his disability, thus indicating he avoided his disability status and the impact it had.

The third model of understanding that Kinavey (2006) describes is that of identity as integrating disability. In this response to SB, the individual with SB has developed an understanding of personal and social meanings of disability and has been able to incorporate them into their sense of self. Individuals with this viewpoint have come to it over time as their conceptions, awareness, and meaning have changed and developed. These individuals are aware of social stigma and are able to work towards self-acceptance. The following quote captures the awareness of social stigma. It comes from an individual with SB who used to ambulate but had recently shifted to a wheelchair for mobility. She states: “There’s something about being able to stand that puts people at ease, in social situations. And there’s something in the way that standing enables you to look at someone eye-to-eye on the same level that changes the dynamic of any
interaction” (p. 1101). She contrasted this with a statement about when she started using a wheelchair: “People are more prone to help me, and it’s kind of ironic because I can get around faster and a little bit better, and more efficiently, and I can certainly carry things, when I’m in my wheelchair, and I can’t when I’m using my braces and crutches, but I think, because people see me walking, they assume I can do more” (p. 1101). She has also been able to situate this in the socio-political context and not completely internalize it. Therefore, she is able to lessen the influence societal attitudes have on her life choices.

**Employment**

Employment is located at the roles level in the Multilevel Model of Identity Content in Context model. The role of employee is an important part of an adult identity and one that many people with SB struggle to achieve and maintain. In the United States, Americans on average work 8.7 hours a day, five days a week, and an additional 5.6 hours on the weekends (Zalaquett, 2009), thus how the average American identifies is often in reference to their job. With unemployment and underemployment being consistent issues for individuals with SB, they do not have the same opportunity as the general public to develop a professional identity. Reported employment rates of people with SB vary among studies due to differing definitions of “employment,” which included full-time work, part-time work, and sheltered employment; differences in participant age demographics; and different sampling strategies. The rates for employment for people with disabilities have been reported as low as 19% and as high as 62.5% (Barf et al., 2009; Bellin et al., 2010; Liptak et al., 2015; Mechelen, Verhoef, van Asbeck, & Post, 2008; Schriner, Roessier, & Johnson, 1992; Simeonsson, McMillen, & Huntington, 2002). Often the definition of employment used by researchers includes full-time work (typically defined as working more than 36 hours a week), part-time work, sheltered work, and sometimes even volunteer work (Bellin et al., 2010), which inflates employment statistics. In studies that
use this broad definition of employment, rates of employment are reported as low 38% (Liptak et al., 2015), up to 45% by Schriner et al. (1992), higher still at 53% by Simeonsson et al. (2002), increasing to rates as high as 56% (Bellin & Rice, 2009) and even as high as 62.5% (Mechelen et al., 2008). The work of Mechelen et al. (2008) broke down the rates of employment in several ways. First, they broke rates down into the categories of those who work in the open market and those who work in a sheltered work environment. Of the 62.5% (85 of 136 participants) who worked, 77.6% worked in the open market and 22.4% worked in a sheltered work program. Second, they reported rates in terms of hours worked per week. Again, of the 62.5% (85 of 136) of participants who were employed, 43.4% were employed at least 24 hours a week, 30.1% worked 24-35 hours per week, and 26.5% worked full-time at 36 or more hours a week. In total, 37.5% (51 participants) of participants were unemployed though 21.5% of these volunteered weekly and 9.8% were engaged in full-time education.

Factors that Affect Employment

Determinants for having paid, full-time work included level of education, hydrocephalus status, IQ, functional independence level, ambulation status, and gender (Mechelen et al., 2008) as well as low intrinsic motivation, which is the ability to carry out an action without external incentive (Zukerman, Devine, & Holmbeck, 2010). Mechelen et al. (2008) report that education level was most strongly linked to employment status, with 72% of those who had higher education working more than 24 hours a week. In contrast, 36.5 of those who received a specialized education and completed no higher education were employed. Of those who had full-time work, males were more likely to be employed than females, with 25% of males and only 11% of females employed. The ability to be independent in self-care was also crucial to full-time employment, with only 3% of those who did not have independence in this area employed full-time. In contrast, 33% of those who were independently able to care for themselves had full-time
employment. In addition, Zukerman et al. (2010) report that people with SB tend to have lower levels of intrinsic motivation than TD peers, which can be another barrier to obtaining and maintaining employment.

**Barriers to Employment**

In the study by Mechelen et al. (2008), participants were asked to report on barriers encountered in finding employment. Of the 51% who reported problems, many had been offered work that was too physically (30%) or cognitively (37%) challenging given their impairments. Another 32% had difficulties accessing transportation to get to work. Many also found the work space environment to be inaccessible (46%).

The most commonly reported barriers to employment were the attitudes of the potential employer and their bias towards people with disability. According to Mechelen et al. (2008), 57% of participants reported this as a problem. Despite documented statistics demonstrating that people with SB do not miss work any more frequently than their non-disabled peers, employers still tend to believe that employees with SB will be less productive and take more sick time. However, it is not clear if employers and potential employers are aware of this.

Schriner et al., (1992) conducted a study on the employment concerns of people with SB and found many barriers to employment. Most of these overlapped with the above noted barriers; however, one major additional issue uncovered was inadequate health benefits offered through employment. People with SB often have higher healthcare needs and rely on health insurance to cover expenses. Those who are unemployed often rely on state Department of Social and Health Services (DSHS) programs and Medicare to help with healthcare expenses. Because these government-sponsored programs tend to be income-based, employment puts these benefits at risk as the individual may end up earning too much and thus lose government aid. Moreover, the insurance provided by employers is often inadequate and comes with copays, premiums, and
deductibles. This requires people with SB to choose to work and risk their government-funded insurance or to not work if they want to be assured that their healthcare needs will be met.

**Psychological and Mental Health**

An individual’s psychological and mental health strongly impacts many aspects of life and can determine which roles one is able to fill. Thus, psychological and mental health is located at the level of roles within the Multilevel Model of Identity Content in Context model. Those with physical disabilities, such as SB, more often struggle to maintain good mental health than the general population (Bellin et al., 2010; DiCianno et al., 2015). Mental health status affects how we view ourselves, our world, and our place in the world, and therefore is highly influential in the identity development process.

**Internal Contributing Factors**

Internally-situated variables include a desire to avoid reality, frustration due to the disability, social isolation, escape seeking, as well as other emotions (Sales, 2000). The development of healthy coping strategies to deal with these issues can be especially difficult for people with disabilities, especially when cognitive impairments are present (Crittenden, 1990). The propensity to internalize often starts at an early age. Children with SB tend to perceive themselves with detriments in the domains of self-worth, physical appearance, athletic competence, social acceptance, and scholastic competence (Shields, Taylor, & Dodd, 2008). Other personal risk factors that are unique to people with SB include the attitude an individual has toward their SB (Bellin & Rice, 2009). Those with more negative attitudes toward their SB tend to have more mental health issues.

**External Contributing Factors**

External variables include factors that occur outside of the individual, such as inaccessible facilities, lack of accessible transportation, and unequal access to opportunities for
participation in a variety of activities, all of which have a strong negative impact mental health (Brislin, 2008). Keeping busy and being productive facilitate a sense of well-being and contribute to a person’s sense of value. Unequal access to employment leads to higher unemployment and underemployment rates can leave to too much free time and too few ways to be productive (Vash & Crewe, 2004), thus contribute to poorer mental health outcomes. Unemployment not only hinders the individual's ability to feel productive, it limits social engagement opportunities through work, which hinders the attainment of a healthy social support network. Another physical barrier is a shortage of accessible transportation. This impedes all varieties of community participation, especially in suburban and rural areas where accessible public transportation is not readily available. A decrease in opportunities to develop social networks tends to start at an early age. Many playgrounds designed for children are not accessible, which hinders youth with SB’s ability to make friends and interact with peers. Opportunities to socialize with TD peers may also be limited if the youth with SB is educated in a special education setting rather than in a mainstream setting.

**Internalizing Disorders**

The above risk factors mean that mental health problems are much more prevalent in people with SB than in the general population. DiCianno et al. (2015) completed a study on depressive symptoms in adults with SB. They found that 25.8% of participants had Becks Depression Inventory-II (BDI-II) scores of 14 or greater, indicating the likelihood of clinical depression. Another 36.3% were already on antidepressants and 63.3% of those on antidepressants still met clinical cutoff rates for depressive symptoms. Based on their results, they estimate that up to 45.7% of adults with SB have clinical depression (DiCianno et al., 2015). Bellin et al. (2010) note that anxiety is also common among people with SB, with a 31% prevalence rate. A study that looked at prevalence rates for depression, anxiety, and stress in
those with SB found that 55.7% of respondents reported sub-clinical levels of depression, 55.7% reported sub-clinical levels of anxiety, with an additional 60.8% reporting stress symptoms (Hayter & Dorstyn, 2013). Hayter and Dorstyn report prevalence rates of 21.6% for depression symptoms in the severe to extreme range, 22.7% for anxiety, and 15.5% for stress. Many adults with SB are aware they have a problem with depression even if they have not been diagnosed. A 2015 survey indicated that 50% of adult respondents thought that they had a problem with depression (Wagner et al., 2015).

Adolescents with SB are more likely to internalize problems, which can lead to depression and anxiety. Mental health variables such as self-esteem, self-concept, and global self-worth are affected by outside influences, which can become internalized (Kinavey, 2007). These variables are strongly influenced by societal messages received by the adolescent with SB. In addition to internalizing symptoms, societal messages can also lead to an internalized concept of disability spread, wherein a youth begins to believe that they are disabled in other ways as well. Often these internalizing symptoms start in the teenage years because adolescents with SB are more vulnerable to developing internalizing disorders, such as anxiety and depression, as well as poorer self-concepts (Holmbeck & Devine, 2010). Börjeson and Lagergren (1990) report that 85% of teens in their study were depressed and that two thirds reported poor self-concepts. Females reported these symptoms more frequently than males. Other studies indicate that 13–18% of adolescents and 41–48% of emerging adults with SB present with depression scores above the clinical cutoff (DiCianno et al., 2015). A study by Bellin and Rice (2009) stated that half of the youth participants reported depressive symptoms, 31% reported anxiety symptoms, and more than half met minimum threshold criteria for both depression and anxiety. This is startling considering only 11% of adolescents in the general population and 10.9% of emerging adults in the general population have depression symptoms (DiCianno et al., 2015). Youth with
depression are more likely to experience depression as adults, which can then affect ability to successfully attend to self-care needs, can adversely affect employment status, and can also negatively affect other life domains (Essner & Holmbeck, 2010).

How these youth view themselves, their SB, and their physical appearance strongly correlated with depressive symptoms and appraisal of self-worth. These strong negative appraisals are influenced by the plethora of societal held myths and misconceptions of disability (Brislin, 2008) and tend to motivate people with SB to put a lot of effort into convincing themselves and others that they are normal. This can be physically and emotionally draining and may exasperate existing mental health symptoms. Appleton et al. (1996) found that self-evaluation of their physical appearance was the biggest predictor of global self-worth. Holmbeck et al. (2010) found that girls are at a higher risk for having a negative view of their physical appearances, whereas both boys and girls are at higher risk of low self-esteem (Holmbeck et al.). In addition, youth with SB are at greater risk of suicidal ideation (Appleton et al., 1996) and an increased number of suicide attempts (Kinavey, 2007). Börjeson and Lagergren (1990) found that females reported suicidal ideation more often than males. This increased risk of suicidal ideation in females could in part be due to the emphasis placed by society on the ideal female body, which those with SB typically cannot begin to live up to.

The impact of poor mental health on people with SB is wide-reaching and it is not just the responsibility of the individual with SB. Mental health symptoms, whether diagnosed or not, can make it more difficult for those with SB to reach independence in self-management of their SB (Bellin et al., 2010). Mental health issues deplete a person’s motivation, making it more difficult to get up in the morning and leave the house (DiCianno et al., 2015).

Resiliency Factors

Despite their many challenges, those with SB show several areas of resiliency in the area
of psychological and mental health. First, substance use disorders in people with SB tend to occur at lower rates (Soe et al., 2012). Alcohol use was reported at 28%, which is much lower than the national average of 56% alcohol use rates for the general population (National Institute on Alcohol Abuse and Alcoholism, 2015). Depression was a risk factor for alcohol use for adults with SB, as those with depression were 4.7 times more likely to use alcohol than those without depression. Rates of marijuana use for youth ages 12 to 17 were also much lower for youth with SB, with rates of 3% compared to 17% in typically developing youth. However, youth with SB who had greater social adjustment were found to be at greater risk of substance use as early as ages 12 to 13 years (Murray et al., 2014). Murray et al. suggest these youth may be at higher risk for substance abuse because being socially well-adjusted, from their perspective, means they may be more likely to fit in with peers who are partying and using substances, which increases the opportunities the youth has to be exposed to and take part in alcohol and substance use. In this sense, being less socially well-adjusted is a protective factor for alcohol and substance use.

A second area of resiliency is overall satisfaction with quality of life (Barf et al., 2007). Research done by Barf et al. indicated that 74% of young adults with SB were satisfied with their quality of life with only 24% indicating that they were unhappy with their quality of life. These rates of satisfaction are comparable to the general typically developing population. Those SB young adults with hydrocephalus were more satisfied with their financial situation and family life than was the general population. However young adults with SB had less satisfaction with their sex lives and their ability to perform their self-care independently; however these differences were statistically small and are to be expected, given the impact of spina bifida on sexual functioning and the higher care needs of those with SB (Barf et al., 2007).
Physical Health

Physical health is not a commonly portrayed theme in identity development literature. Nevertheless, it is important in the context of disability identity development because so many people with SB have secondary, ongoing, and chronic health-related issues. The impact of physical health is situated at the level of roles in the Multilevel Model of Identity Content in Context model because it impacts what roles a person with SB may or may not have access to. When a person has health issues, they may not have the same access to a variety of roles, including employee, parent, and various other social roles as healthy individuals due to limitations in energy and time caused by health conditions. They may also internalize the role of “sick” and begin to self-limit what other roles they choose to participate in (Marks, 1999). The roles a person has are quite tied to identity. Often when people are asked about themselves, their first answers are the roles they hold, for example “I’m a student,” “I’m a teacher.” Therefore, chronic health-related conditions related to SB, which limit the roles available, very much contribute to one’s identity.

Health Conditions

Many adults with SB report health-related concerns specific to their SB, such as consequences of chronic hydrocephalus, continued issues with incontinent bowel and bladder, poor circulation, and pain due to abnormal strain on hip and knee joints as well as joint over-use (Thomson & Segal, 2010; Wagner et al., 2015; Webb, 2010). Issues with skin integrity lead to pressure sores, which occur in 62% of adults with SB. A pressure sore can take anywhere from weeks to months to heal, depending on its severity. Where a pressure sore is located on the body also affects how it impacts the individual. For example, a sore on the buttocks can cause a person who uses a wheelchair to be on bedrest because for the duration of the healing process, since all pressure needs to be relived until the sore is gone. A decrease in strength and mobility over time
in those who ambulate often occurs as well. Up to 20% of those who ambulated in their youth need to use a wheelchair for mobility by the time they are 30 years old (Webb, 2010).

Obesity and obesity-related health issues are also a problem for people with SB. Obesity rates for teens and adults with SB range from 34–64%, with lower obesity rates for people who ambulate and higher obesity rates for wheelchair users (Dosa, Foley, Eckrich, Woodall-Ruff, & Liptak, 2009). This high incidence of obesity is due to a sedentary lifestyle; neuroendocrine issues related to hydrocephalus and the Chiari malformation; less lean body mass and lower basal metabolic rates than non-disabled individuals (Dosa et al., 2009). Moreover, obesity is directly associated other health issues, such as Type II Diabetes, coronary heart disease, stroke, heart failure, and cancers (Adler & Stewart, 2010). Adults with SB older than 35 years have hypertension prevalence rates of 40%, which is higher than that of the general population, which has prevalence rates of around 29% (Webb, 2010). Dosa et al. (2009) report that those with SB and obesity tend to have issues with an increased number of preventable secondary medical conditions, such as pressure sores, gastro-esophageal reflux disease, and decreases in ability to be mobile and independent. They may also experience more frequent incidences of psychosocial and mental health issues such as social isolation and depression (Dosa et al., 2009).

On average, adults with SB are overall less physically healthy than the general population. Adults with SB tend to have lower cardiorespiratory endurance and poorer muscle strength as well as higher body fat percentages than the TD population (Oliveira, Ja´come, & Marque, 2014). Many do not eat a healthy diet, with up to 75% reporting not regularly eating whole grains, fruits, and vegetables as compared to 12% of the general population (Soe et al., 2012). Those with SB do not exercise regularly, with 74% reporting no physical activity in the last month as compared to only 22% reporting no physical activity in the general population. In addition, the sedentary lifestyle for people with SB often included watching at least three hours
of television a day (Soe et al., 2012). These poor health-related lifestyle choices are contributing factors to a vast number of preventable health concerns and problems.

The rate of hospitalization for teens and adults with SB is 20% higher than that of the general population (Liptak et al., 2015). Adolescents with SB have a 19.4% higher rate of admission to a hospital and adults with SB have a 12.4% higher rate of admission to hospitals. The authors report that these rates are up to 4.7% higher for people with SB who have hydrocephalus due to shunt malfunction. Common reasons for hospitalizations include infectious disease, musculoskeletal reasons, renal disease, urinary tract infections (UTI), pressure sores, and gastrointestinal issues, (Hunt & Oakeshott, 2004; Liptak et al., 2015). Important to note is that approximately 33% of the hospitalizations reported were from issues that could have been prevented (Liptak et al., 2015).

**Barriers to Healthcare**

Barriers to healthcare access are often due to a lack of accessible transportation or unavailability of an adult care provider trained in the needs of adults with SB (Liptak et al., 2015). Difficulties accessing healthcare impede opportunities for the education doctors might provide on the importance of preventive behaviors. Liptak et al. (2015) report that 71% of people with SB have difficulty accessing healthcare, and 41% of these cases are due to lack of available resources, including adult doctors who work with adults who have SB. Another 64% had difficulties related to lack of transportation. The low socio-economic status (SES) of many with disabilities also impacts access to care as many adult providers do not accept state-funded insurance. When those with disability and low SES do access care, they tend to receive less information and less positive conversation from their providers (Lott, 2002).
Implications of Physical Health

There are many physical health ramifications on the individual with SB. Frequent hospitalizations limit the number of opportunities those with SB have to participate in their communities. A lack of information and open conversation from providers may prevent those with SB from learning the skills and strategies they need to live the healthy lifestyles that will allow them to prevent a variety of health issues. The health issues that people with SB tend to deal with often put those with SB into the role of “sick” and “dependent,” which limits their access to other roles (Marks, 1999). Internalizing the roles of “sick” and “dependent” can also cause the individual with SB to self-limit the other roles to which they have access.

These health concerns contribute to mental health issues because people with SB must ultimately balance independence with a need for help. People with SB have an overall significantly impaired health-related quality of life (HRQoL). HRQoL includes measures of physical functioning, the use of healthcare, and state of general health which can be difficult to deal with (Rofail et al., 2014) and contribute to depression. The cumulative effect of long-term medical stressors, as well as their unpredictability, take a toll on psychological well-being (Hayter & Dorstyn, 2013). Needing extra assistance to help care for medical issues or other needs, such as transportation or reaching things at the grocery store, can lead to feelings of incompetence, or can make the individual with SB feel like they are an inconvenience to others (Van Daalen-Smith, 2006).

Family System

Family systems are another area of identity formation for people with SB. As family functioning is highly dependent on societal norms, family systems fit within the outermost level of the Multilevel Model of Identity Content in Context model. An individual’s values, morals, and traditions are influenced by family even before birth (Galliher et al., 2017). As children are
exposed to their family’s culture, their identities are shaped setting the trajectory for identity development. An adult’s sense of identity continues to be shaped by their family of origin as they balance where they came from with where they are going.

**Parenting**

There are many parenting styles from which families may choose, but parents are more likely to use higher levels of intrusiveness and psychological control over a child who has SB and who may have an authoritarian parenting style (Holmbeck & Devine, 2010). This may be due in part because a parent’s view of societal attitudes and beliefs can highly influence how a child with SB is raised. If they believe that the child with SB is more fragile, less capable, and more vulnerable to social influences, they may be more likely to be intrusive. They may also be more intrusive because they are concerned about the well-being of their child and want to ensure their care, medical, and educational needs are met. The cognitive issues that are common in people with SB may make it more likely that parents use an authoritarian style, as it is what the child responds best to. An authoritarian style is more directive and assertive than other parenting styles, so tends to be very clear. When a child has cognitive difficulties, the clarity offered by an authoritarian style can be helpful for the youth as it promotes comprehension of parental requests.

**Family Stress**

When a child with SB is born into a family, the entire family unit is impacted. According to Holmbeck and Devine (2010), both parents tend to experience global distress, but fathers tend to have higher levels of distress than mothers. Both parents are more likely to feel less parental satisfaction and feel less competence as parents when they have a child with SB. They may feel more isolated, be less adaptable to change, and have a more pessimistic viewpoint. One of the best predictors of family stability and how parents will deal with the stress of raising a child with
SB is the quality of the parental relationship before birth (Holmbeck & Devine, 2010). Siblings of the child with SB are also affected and tend to have more adjustment problems, greater concern for health of the sibling with SB, and emotional upset in relation to experiences of SB than when SB is not present in a sibling (Holmbeck & Devine, 2010). For example, a sibling of a youth with SB may find it scary or upsetting when the sibling with SB needs a surgery. They may also get frustrated when they see accessibility as barriers to their sibling with SB’s ability to participate in an activity.

Another contributor to family stress is financial strain and the costs associated with having a child who has a disability. According to Rofail, Maguire, Kissner, Colligs, and Abetz-Webb (2013), people with SB have an average lifetime of medical costs ranging from $285,959 to $378,000. Medical expenses include doctor visits, hospital stays, surgeries, therapies, medications, and durable medical equipment such as crutches or wheelchairs. Non-medical related costs of SB average $52,570 and include services such as special education and other developmental support programs. Insurance and other government funds help pay some of these costs, but many are out-of-pocket expenses for the family. Another cause of financial stress comes from the reduced hours worked by parents after having a child with SB. Mothers report up to a 14 hour per week reduction in work hours, while fathers reported up to a 5 hour per week reduction. This loss of work hours can cost the family up to $162,124 in lost wages over a lifetime (Rofail et al., 2013). The combination of costs and lost income can be devastating for a family.

**Family Resiliency**

Despite the extra stresses and financial strains of raising a child with SB, families also demonstrated an extraordinary amount of resilience. Family cohesion levels remain comparable to families of children without SB (Holmbeck & Devine, 2010). Other variables such as parent-
child conflict, maternal acceptance, paternal parenting behaviors, and maternal and paternal behaviors such as positive engagement, positive affect, and conflict behavior also are demonstrated at comparable levels (Lennon et al., 2015). In addition, adolescent-parent conflict during puberty remains low compared to that in typically developing youth and their parents who typically see an increase in parent-youth conflict (Holmbeck & Devine 2010; Jandasek, DeLucia, Holmbeck, Zebracki, & Friedman, 2009; Lennon et al., 2015). Siblings of children with SB also demonstrate resilience in that they have an increased ability to empathize with others and greater appreciation of their own physical ability (Holmbeck & Devine, 2010). Thus, even though raising a child with SB can be stressful, it is not necessarily detrimental to family health and functioning.

**Transition**

Transition refers to the period in which youth are moving towards young adulthood. It encompasses the areas of intersecting domains of everyday experiences, microcontents, and behavioral episodes of the Multilevel Model of Identity Content in Context model. Microcontents are specific behaviors and individual situations that occur as a result of the interactions of all the layers contained in the Multilevel Model of Identity Content in Context model. Transition is specifically defined as “the developmental period when the adolescent becomes a young adult while increasing self-management of their chronic condition and independence in their social environment” (Ridosh et al., 2011, p. 866). It includes many tasks such as management of self-care, becoming an adult, employment, and managing quality of life (Brislin, 2008). Thus, it is connected to and influenced by the themes discovered in this work

**Transition and SB**

Transition is a challenging time to navigate for most adolescents and their families, and when SB is a factor, it can become even more complicated. Compared to their TD peers,
transitioning youth with SB tend to be behind in the milestones of leaving home, attending college, maintaining employment, and having romantic relationship experiences (Zukerman et al., 2010). Zukerman et al. report that 77% of transitioning youth ages 19–25 with SB still live at home as compared to only 59% of TD youth 17–27 years of age. Females with SB are more likely to live independently than males (Holmbeck & Devine, 2010). Those with SB are less likely to go to college, with an enrollment rate of 49% compared to 66% of TD youth. They have lower rates of full- or part-time employment at 34%–41%, compared to TD youth who have an employment rate of 75%. Only 68% of youth with SB have had experience with romantic relationships as compared to 90% of their TD peers.

The struggle to transition to adulthood is complicated for youth with SB. Cognitive impairments in executive functioning can make a variety of activities more difficult. They may struggle with poor planning skills, difficulties initiating action, and challenges with sustaining attention, all of which can make learning new tasks tough. Deficits in these areas can also make managing multiple simultaneous adult responsibilities more challenging (Zukerman et al., 2010). Difficulties with executive functioning can also make completion of high school difficult and college attendance nearly impossible. Lack of academic accomplishment contributes to poor employment opportunities (Verhoef et al., 2005). IQ scores are also a factor, since an IQ over 85 is associated with better education and employment outcomes (Barf et al., 2009; Mechelen et al., 2008). In one study, a parent commented on the impact of his son’s cognitive impairments and how they complicated his transition:

“He’s almost 19 years old. Your typical kid would be off in college…with some guidance. But developmentally, he’s at a 10 or 11-year-old level…He looks like a full-grown adult person, but cognitively, that’s not all there. He thinks he’s much more
independent than he is…he still needs somebody that’s coordinating (his care).” (Berrya et al., 2013, p. 215)

Adaptive behaviors are those behaviors that allow individuals to compensate for shortcomings. Adaptive behaviors and strategies allow those with SB to minimize the impact SB has on their everyday life. They are crucial part of the transition process for adolescents with SB in order for them to make a successful transition to adulthood. There are several strong predictors of adaptive behavior in transition-age youth with SB including mastery motivation, executive functions, and executive behaviors. These factors account for 37–47% of the variance in measured outcomes for how well teens with SB transition into adulthood (Warschausky, Kaufman, Evitts, Schutt, & Hurvitz, 2017). Another is the environment that parents create for their child with SB, which can either promote achievement and independence or hinder the development of independence (Simeonsson et al., 2002). Parental over-helping and intrusiveness is one variable that can hinder autonomy development, because it instead fosters the further dependence on the parent (Lennon, Klages, Amaro, Murray, and Holmbeck, 2014; Zukerman et al., 2010). SES is linked to ability to attend college with those who have higher SES backgrounds being more likely to attend. While low SES may hinder a family’s ability to encourage a youth with SB to reach these milestones (Zukerman et al., 2010).

**Factors of successful transition.** The afore mentioned statistics look grim; however, many young adults with SB are capable of achieving independence and successfully moving into young adulthood. Newer research shows that youth with SB tend be about two years behind in psychosocial development than their TD peers; however, they do tend to catch up over time in most areas (Lennon et al., 2015). Children with SB can catch up in academic competence and participation in family. For males, social acceptance and perception of physical appearance eventually becomes similar to that of their TD peers, though the gap for females remains
(Holmbeck et al., 2010). This may be due to the emphasis placed on physical appearance of women in American society. In American society, girls from a young age are bombarded through magazines, television, and social media with images of what is considered “beautiful.” Often the SB body falls short of this ideal and thus contributes to negative perceptions of body image, which in turn can influence social acceptance, actual or perceived.

There is evidence of resiliency in the fact that though prevalence of depression tends to increase in adolescence for TD youth, for those with SB it does not (Holmbeck et al., 2010). This could be reflective of the lower teen-parent conflict found in families where the teen has SB. It could also be due to the fact that psychosocially, adolescents with SB tend to be about two years behind developmentally, causing the increase in internalizing symptoms that leads to teenage depression for TD youth to occur a bit later in development for youth with SB (Holmbeck et al., 2010). Further research needs to be done to better understand this relationship.

In their research, Ridosh et al. (2011) identified three themes essential to the transition process: the struggle for independence, experiences with stigma and limiting social interactions, and building inner strength. These themes are helpful in identifying the areas in which youth with SB show resilience and in which areas intervention may be helpful. Ridosh et al. (2011) make several suggestions to support youth and promote the successful development of skills as they transition to adulthood. They recommend providing opportunities for children with SB to practice independence such as sending them to camps. Camps give kids with SB opportunity to interact with others who also have SB and to exchange ideas. One youth noted:

It was hard but the counselors were there but didn’t baby you. You were given goals to help yourself, to move forward. I guess just meeting others (with spina bifida) also helped. There were older kids there that I saw could do things themselves. (p. 869-70)

They also suggest giving youth opportunities to manage their self-care at early ages, a youth
commented on this in relation to learning to self-catheterize, “My dad made sure too...my parents should have made me do it sooner. I was almost in 6th grade when I started catheterizing,” (Ridosh et al., p. 869). As incontinence is the largest barrier to independence for many people with SB (Brislin, 2008; Lindsay, 2014; Ridosh et al., 2011), opportunities to learn from others, strategize about self-care techniques, and practice them are crucial. The following quote sums up the importance of both:

I didn’t want to get up if I messed. They really thought I could control or should . . . and I did try new things but in gym it was hard because I wore a diaper...people not feeling I could do normal things because I was in a chair, just the kids making fun, the looks. I didn’t really know anybody else with spina bifida unless I came to clinic. (p. 870)

Giving youth opportunities to learn from others, be exposed to what others with SB can and are doing, and to practice self-management techniques will foster the process of increasing independence.

A second theme identified by Ridosh et al. (2011) was experiences with stigma and limiting social interactions. Transitioning youth are aware of the stigma around disability and compare themselves to others. Because youth with SB often do not have a SB peer group, comparisons are made to TD adolescents. This often brings an increased awareness to the stigma of disability as well as a sense of differentness (Shields et al., 2008). When talking to those without disability, it often puts them in the position to be the voice of people with SB, which may feel awkward and uncomfortable for the person with SB (Van Daalen-Smith, 2006).

Transitioning youth with SB are aware that their incontinence, mobility limitations, cognitive impairments, and other disability-related issues make participation in social activities difficult and sometimes uncomfortable (Lindsay, 2014) and thus may limit their participation. The awareness of stigma, lack of opportunity, and limits set by others, as well as their awareness of
their disability often make transitioning youth with SB feel more disabled than they are, which further impedes their ability to successfully transition on a trajectory matching that of TD youth.

Finally, the third theme identified by Ridosh et al. (2011) is that of building inner strength. This theme captures the importance of family, faith, and focusing on the positive. It highlights the importance of recognizing and building on inherent strengths, focusing on positive aspects, and a developing of a self-perception that characterizes those with SB as normal despite having disability (Lindsay, 2014). Focusing on strength-based abilities, the maintenance of friendships and strong family relationships are areas of resilience for youth with SB that promote a healthy transitional period.

The theme of transition interacts with a variety of other identity development themes. It interacts with the theme of employment as the youth with SB who have cognitive impairments struggle with school due to low IQ and other cognitive difficulties and is not able to attend college, thus limiting employment opportunities. As youth transition and attempt to fit in with their TD peers, transition interacts with the theme of psychosocial. The theme of transition is also influenced by the theme of family in how the parents are promoting or hindering the development of independence. The theme of health, both physical and mental, also interacts with the theme of transition as health promotes or hinders a successful transition into adulthood.

**Sexuality**

In the Multilevel Model of Identity Content in Context model, sexuality is experienced as both a role and as one of many of intersecting domains. Sexuality is a crucial element to the development of an adult identity for those with and without SB. When an ableist lens is applied, many with SB may be perceived as asexual and may even perceive themselves as such (De Vyldera, Van Driela, Staal, Weijmar Schultz, & Nijman, 2004; Van Daalen-Smith, 2006). They and others may also believe that a relationship with a person with SB is an inconvenience and
those without disability may perceive people with SB as incomplete humans incapable of being in a romantic relationship (Van Daalen-Smith, 2006). Though these ableist thoughts are common within society, they are far from the truth. Those with SB who have lesions at or below an S1 level, in general, have normal sexual functioning (De Vyldera et al., 2004), while those with lesions between L3 and L5 may have some variability in their sexual function (De Vyldera et al., 2004). According to De Vyldera et al. erogenous zones in the areas above the level of lesion, such as the nipples, remain unaffected by SB and can bring about sexual pleasure during intercourse.

As with any other human population, many, if not most, adolescents and adults with SB have had sexual thoughts and experiences. As many as 70% of people with SB have wanted sexual contact of some kind, and 22% have had sexual intercourse within the last year (Verhoef et al., 2005). Though people with SB are sexually active, they are not as active as those without SB. Of young adults with SB ages 16–25 years, only 22% of them have had sexual intercourse, whereas 47% of TD high school students have engaged in sex (Murray et al., 2014). Murray et al. also found that 78.0% of young adults with SB reported never having had a sexual partner compared to only 28.3% of the those without SB. At least 83% of females with SB report that they have an interest in the opposite sex and 75% of them report experiencing sexual desire, however, only 38% reported having had sexual intercourse (De Vyldera et al., 2004). Unfortunately, no studies were found that discussed youth SB who are other than cisgender and heterosexual.

The main reason for the discrepancy between rates of sexual intercourse between those with SB and those without is self-confidence. This is followed closely by concerns around incontinence (Cullerès, Sugranyes, & Bolívar, 2005; Kinavey, 2007; Verhoef et al., 2005). Those with SB who are continent are twice as likely as those who are incontinent to be in a romantic
relationship (Verhoef et al., 2005). Often, people with SB use products such as disposable diapers or pads to mitigate the impact of neurogenic bowels and bladders. Uncovering the use of these products, in the context of a romantic relationship, can be embarrassing and can be a deterrent to pursuing romantic relationships (Kinavey, 2006). A female participant in one study said, “Like right now, I wouldn’t consider myself a sexual person, cause I have so much anxiety stemming from how my bowel is acting” (Kinavey, 2007, p. 155). The trust needed to disclose issues such as incontinence is immense and takes time to develop. This too often shapes how those with SB view sexual intimacy and how willing they are to experiment. Another participant had the following to say,

My friends treat sex a lot differently than I do.... It’s on a much more freer, casual basis....I have to build a certain level of trust with someone, before I can even think about that. Just because it does take a certain level of maturity, to deal with, like, you know, ‘Hey, so I have a bladder disability’... I don’t think I’m going to be able to find that casually. (Kinavey, 2006, p. 1102)

Abilistic ideas also get in the way of romantic relationships and sexual behaviors. As noted above, people with SB are often perceived as asexual and incomplete. In addition, many prospective partners may believe it is inconvenient to be in a relationship with someone who has SB (De Vylde et al., 2004; Van Daalen-Smith, 2006). These kinds of abilistic thoughts drive all sorts of actions and beliefs. When a person with more severe SB uses a wheelchair, the influence of abilistic thought becomes more evident as they often get treated differently.

Because of me being in a wheelchair, I was treated differently by guys. . . I had a guy friend, who was friends with this other guy that I had a crush on . . . this other guy told my friend, that he wouldn’t look at a person like me because of the fact that I was in a
wheelchair. . . He basically told him, “Why would I want to be with her? She can’t even stand up.” (Kinavey, 2007, p. 155)

Those with SB may have also internalized abilistic views and thus doubt the motives of those they get in relationships with or doubt their own sexual attractiveness.

If I have a relationship with a guy . . . it’s happening, but it’s really not because in the back of my mind, I’ll still be questioning, like, ‘Well, why the heck do you want to, like . . . be with me? What’s the catch . . . like, what, what’s your motive?’ (Kinavey 2006, p. 1098)

Several other variables also contribute to sexuality and sexual behavior in those with SB. Those with better social skills and who demonstrate better social adjustment in middle school have more sexual partners in adulthood (Murray et al., 2014). Those with hydrocephalus also demonstrated more difficulties in developing romantic relationships and less sexual activity than those without it (Verhoef et al., 2005). Statistics show that those with hydrocephalus are less often in a romantic partnership and are general less sexually active (Verhoef et al., 2004). This is in part due to the likelihood of impairment of sexual functioning including sexual excitement, erection, ejaculation, and orgasm in males (Verhoef et al., 2004). It is also potentially related to higher rates of executive function impairment (Zukerman et al., 2010). Executive function impairment can cause difficulties with initiating behavior, planning and organizing strategies to solve complex problems, and monitoring and evaluating behavior of self and others (Zukerman et al., 2010). These difficulties then negatively impact social skill development as well as an individual’s ability to demonstrate healthy levels of social adjustment. Difficulties with social skills and lower levels of social adjustment are negatively associated with the number of sexual partners one may have in adulthood (Murray et al., 2014). These deficits in executive functioning
are highly correlated with having hydrocephalus and are less likely to be present when there is an absence of hydrocephalus (Veenboer et al., 2013; Liptak et al., 2015).

**Psychosocial**

Psychosocial ramifications of SB exist when elements of the individual interact with elements of the social environment. Psychosocial aspects of identity can be found at every level of the Multilevel Model of Identity Content in Context model. These ramifications often serve to further exasperate disability-related issues and can cause a variety of difficulties. People with SB need opportunities to interact socially, however there are a multitude of factors that present barriers to social participation. Often those with SB have lower SES, which means they have less money to spend on social and leisure activities (DiCianno, Gaines, Collins, & Lee, 2009). Pain and internalizing symptoms such as anxiety are also barriers to participation (Essner, Murray, & Holmbeck, 2014). Other disability-related factors, discussed in detail earlier in this paper, such as limited mobility and incontinence, are additional barriers to social participation (Essner & Holmbeck, 2010).

**Cognitive Functioning**

Multiple studies note that executive functioning is a mediating factor for social participation and acceptance (Stubberud, Levine, Langenbahn, Stanghellie, & Schanke, 2014; Kelly, et. al., 2011; Lennon et al., 2014; Warschausky et al., 2017). This is because those with higher executive function tend to have increased social skills and ability to fit in with peers. They make friends more easily and are able to behave in socially appropriate ways. Executive functioning allows for the ability to read social cues, follow social norms without impulsivity, pay attention to conversations, and exhibit an ability to think before they act and speak. These are important skills for succeeding in society and being perceived as normal. For those with hydrocephalus, the accompanying impairment in executive functioning results in fewer positive
experiences with their non-disabled peer group likely because of poor social skills (Essner & Holmbeck, 2010). Fewer opportunities to engage socially results in fewer opportunities to learn and practice social skills they so desperately need to develop.

Youth with SB tend to have low intrinsic motivation which leads to a plethora of impaired participation in many activities. They tend to be socially immature and passive, have fewer friends, are less likely to have social contacts outside of school, and date less during adolescence (Holmbeck et al., 2003). Holmbeck & Devine (2010) have also found that youth with SB are more dependent on adults for help, less likely to act on their own accord at home, and have less intrinsic motivation at school. They also found that this is truer for boys and those individuals with lower levels of intelligence. Lack of intrinsic motivation was the strongest predictor of psychosocial functioning, therefore those with less intrinsic motivation were less likely to have healthy adaptive social skills. Therefore, children with SB may need more adult encouragement to participate in social activities, to voice their thoughts, and act independently (Essner et al., 2014).

Social Deficits

Social difficulties for people with SB are often evident most strongly in childhood (Holmbeck et al., 2003). Children who exhibit social difficulties are more prone to develop adolescent onset depression (Holmbeck et al., 2003). Having positive experiences with family, peers, classmates, and teachers is a protective factor against internalizing symptoms; however, youth with SB tend to have fewer of these positive experiences especially at school and with their peers (Essner & Holmbeck, 2010). Being the lone member of a family with SB can feel isolating as well, since the family may unwittingly hold to the same oppressive thinking as society (Kinavey, 2007), exacerbating feelings of differentness in the youth with SB. Kinavey states that higher rates of social impairment, poorer educational outcome, and less independence
from family or caregivers may also play a part in poorer mental health as well as the youth’s level of satisfaction with family functioning. Bellin and Rice (2009) adds that families with poorer levels of family functioning are also more prone to experience mental health symptomology.

The number and quality of friendships for youth with SB is impacted by the disability. Stubberud (2017) found that youth with SB tend to have fewer friends and are likely to associate with children who are younger than they are rather than children their own age. Other studies have found that as many as 33% of youth with SB have friends who are 1 to 5 years younger than them (Marques, Maldonado, Peralta, & Santos, 2015). The quality of friendships that children with SB experience is often lower than friendships between children without disability. Youth with SB tend to spend less time with friends and get less companionship, security, and closeness from their friendships (Devine et al., 2011). Youth with SB typically feel less emotionally supported by friends and family compared to TD youth. The lack of social competence in youth with SB skews how they perceive their friendships (Devine et al., 2011). Youth with SB may identify a best friend but find that the identified best friend does not reciprocate (Stubberud, 2017; Devine et al., 2011).

Incontinence is also an expressed barrier to making and maintaining friends (Fischer et al., 2015). Youth who could independently take care of their need for catheterization were more successful in making and maintaining friends. This is because the fear barrier of having an accident or being seen catharizing that keeps youth with SB from wanting to go to someone else’s home or attending a sleepover has been removed (Fischer et al., 2015). One youth explained he avoids attending sleepovers because, “If they see what’s in the garbage, then they’ll ask me questions. I don’t really want to explain it to them” (Fischer et al., 2015, p. 960). Youth tend to want to hide their incontinence issues and will keep it a secret. One female youth noted
“If I go in there and there are girls in the bathroom, I’ll walk out just so they don’t see my catheter” (Fischer et al., 2015, p. 959). A male youth explained how he lets his friends think that SB means only that his legs do not work: “[P]eople know about my disability but I make them think that it’s only my legs that are part of it” (Fischer et al., 2015, p. 959). In this way, he keeps his incontinence hidden.

Though one-third of youth with SB may experience difficulties making and maintaining friendships, the majority of youth engage in many social interactions in and out of school. In fact, many youth with SB have strong and healthy friendships, often at rates similar to that of their TD peers (Zukerman et al., 2010). They report that the support they receive from friendship is important and comes in many ways. Friends often tangibly help with tasks and they offer empathy and a sense of understanding (Antle, Montgomery, & Stapleford, 2009). Good friends also tend to treat the person with SB like a “normal” person which facilitates a sense of fitting in (Antle et al., 2009). One youth noted that she appreciates her best friend because “[s]he treats me like a normal kid. She does things with me like she does with other people” (Antle et al., 2009, p. 102). Though keeping secrets about disability-related deficits is tempting, many youth with SB are less guarded about their difficulties. Some are even honest and open about their need for catheterization, as one 9-year-old stated: “I just decided to tell them before they found out and got shocked and ran away screaming” (Fischer et al., 2015, p. 959).

The result of these hardships in youth is that a strong social network is often not developed. Lacking a social support network is detrimental to self-esteem, identity development, and body image, which in turn affect success in adjusting to disability (DiCianno et al., 2015; Kinavey, 2007; Van Daalen-Smith, 2006; Shields et al., 2008). Even in adulthood, those with SB tend to continue to struggle socially and in general have less opportunity to interact with peers (Stubberud, 2017). In addition, people with SB who use wheelchairs often find it difficult to
make friends, since potential new friends cannot see past their wheelchairs. One person with SB expressed frustration when trying to make friends due to her use of a wheelchair “People they just kind of like, they look at me and they are like…okay…the chair is all they see.” (Fischer et al., 2015, p. 959). Thus, choosing activities are important because many activities decreases the impact of disability, thus serving as equalizers, and enhancing opportunities to develop healthy friendships. Physical activities such as swimming (Antle et al., 2009), passive activities such as watching TV, and interactive activities such as playing a board game tend to provide equalizing experiences (Marques et al., 2015).

**Community Integration**

Another psychosocial aspect that affects identity development is access to and integration within the community. A study by DiCianno et al. (2009) used the Craig Handicap Assessment and Reporting Technique-Short Form (CHART-SF) to measure physical and cognitive independence, mobility, social integration, activity level, and financial status. They collected data from 208 adults with SB: 84 could walk, 82 used a manual wheelchair, and 42 used a power wheelchair. They found that as disability severity increased the scores in the content area of physical independence decreased. As few as 8% of wheelchair users with SB and 31% of those with SB who could walk reported driving independently. In addition, as little as 38% of power wheelchair users and 57% of manual wheelchair users have access to accessible transportation, limiting community integration. In the domain area that measures social integration all three group had much lower scores than TD peers. Young adults reported difficulties with participation in a variety of activities. In one study, 42% of young adults with SB had difficulties with leisure activities, 32% had difficulties visiting family and friends, and 37% had difficulties attending work or school (Barf et al., 2009).
Living independently away from parents is often a goal and is interpreted as a marker of successful transition into adulthood. However, becoming independent in living is a hurdle for many with SB. Young adults with SB are less likely to move out of their parents’ homes at rates typical for their peer group. As discussed under the heading of transition, earlier in this chapter, young adults with SB are less likely to move out of their parents’ homes and to attend college. Studies looking at living arrangements of adults with SB vary in their findings. In some studies, as few as 16% live independently (Barf et al., 2009; Barf et al., 2007) in others up to 40% of those with SB were living independently (Hunt & Oakeshott, 2004). Females with SB were twice as likely as males to live independently (Hunt & Oakeshott, 2004; Liptak et al., 2015). For others with SB, living arrangements remain dependent. Up to 75% of adults with SB live with family (Liptak et al., 2015) and 31% are living in an institution, independent living center, or sheltered home (Barf et al., 2009).

The same personal and environmental barriers that have been discussed in other sections of this chapter also hinder participation in community-based activities (Bloemen et al., 2015). Personal variables such as hydrocephalus and shunting status and accompanying cognitive impairments. As many as 40% of adults with SB list their physical impairments as a barrier to participation in the community (Barf et al., 2009) as wheelchair use status also greatly affects one’s ability to drive and necessitates accessible facilities and activities. The personal factor of a lack of intrinsic motivation and poor executive function (Zukerman et al., 2010) make it difficult to find and plan outings. Incontinent bladder and bowel and mobility limitations also continues to be a barrier (Ridosh et al., 2011; Börjeson & Lagergren, 1990; Barf et al., 2009). Lower ratings of perceived social competence compared to TD populations also proved to be a barrier to community activity participation (Marques et al., 2015).
Access to the community is impeded by many limiting factors which dwell within the environment. Limited long distance transportation was mentioned by 36% of people with SB and issues with accessibility was listed by 42%, these were the largest barriers to participation in community-based activities (Barf et al., 2009). Those with hydrocephalus and a higher level of lesion, as well as those who use a wheelchair, experience more difficulties in participation because of a lack of long-distance transportation (Barf et al., 2009). In addition, the accessibility of buildings was often a barrier (Barf et al., 2009). DiCianno et al. (2009) hypothesize that a general lack of acceptance from other members of society and the perpetuation of abilistic myths is the largest barrier to social integration. Bloemen et al. (2015) report that attitudinal barriers of others are the largest barriers to community participation for those with SB. Another problem may be low SES and available extra funds (Barf et al., 2009; Zukerman et al., 2010) of adults with SB, 17% listed financial limits as a barrier to community participation (Barf et al., 2009). This lack of money could directly correlate to inability to drive, since adaptive vehicles can be quite costly. In addition, assistive and adaptive devices such as handcycles and sports wheelchairs are expensive and not covered by insurance.

**Tying it All Together**

A case study by Kinavey (2006) provides an example of how the themes of identity development impact the individual with SB. Through the story of a 19-year-old male who has SB one can see the many places of his life that were impacted by the themes uncovered in this work. The themes of psychosocial, transition, family, physical health, mental health, view of disability, and impact of others wove together creating for him a complex web of experiences that have shaped him into who he was at the time of his interview. As a child, this man’s lesion was low enough that he could walk. However, due to orthopedic issues (theme of physical health) he had to start using a wheelchair for mobility in late elementary school. In many ways the wheelchair
made him feel conspicuous and highlighted that he had “different than” status (themes of view of
disability and impact of others). He commented that:

Kids were always a little nervous. Some of that nervousness, you know, turns into, I
don’t know, I don’t want to say it turns into hatred. They just don’t understand
and don’t know how to deal with people being in a chair. (p. 1099)

In middle school he found himself to be the only one with a physical disability in his school,
furthering his experience of isolation. He had already been dealing with some depression and the
isolation he experienced at school worsened the condition (the theme of psychosocial which
highlights the interaction between the themes of impact of others and mental health).

It was pretty awkward. ’Cause I was the only one that had a physical disability. . . I was
dealing with depression and I was just really quiet, isolated loner, and being stuck in a
situation where you can’t exactly socialize with the other kids in your class, it just made
it all worse. (p. 1099)

By eighth grade the stress of not fitting in, illness, hospitalizations, difficulties in school, and
social isolation had become too much and he attempted suicide. Here the themes of psychosocial,
physical health, transition, intertwine and impact the theme of mental health

I was having difficulty at school. My grades were falling, and I was failing, like, most of
my classes. I was in and out of the hospital constantly, dealing with medical issues and I
didn’t really get a clear idea of what was happening to me, whether it was something
serious or whether it was just growing up or I was aging, going through puberty. But I
just had a lot of emotions that eventually got too intense, and I just couldn’t take any
more. (p. 1100)

Eventually he was able to access mental health services. By the time of this case study, he was
19 years old and doing much better.
His is a strong example of how the nine identity development themes identified in this work and the personal and environmental variables they contain impact an individual. From a young age he experienced himself as different and not fitting in. Society understood him as different due to his disability and he internalized this. He also experienced health issues, multiple hospitalizations, and disability-related care needs, all of which can be stressful and can exasperate the feelings of being “different than.” His multiple hospitalizations and care needs also limited the number of opportunities he had to participate in social activities. Missing school due to medical care needs, combined with possible learning difficulties, negatively impacted his ability to achieve in school, furthering his experience of feeling like, and even identifying as a failure. In total, these experiences led this young man to feel depressed and isolated, which led him to a suicide attempt.

Like the elements of the Multilevel Model of Identity Content in Context model, the themes of identity development exist in a multi-point interrelation context. This context includes points of resiliency and areas of vulnerability as well as the many situations a person with SB encounters on a daily basis in a variety of contexts thought their life. As the elements and situations interact, the person with SB makes decisions and carries out behaviors, which also interact and interrelate with situations and contexts. This cycle starts the day a person is born and progresses and changes as the child learns, grows, and develops. As the person develops so does their identity, and as the person changes, again so does their identity. Understanding the many complex interrelationships is the first step in understanding how one becomes who they are and how they view and come to understand their SB.

**Implications for Professionals**

**Mental Health Providers**
There seems to be higher rates of internalized disorders such as anxiety and depression for those with SB and there are certainly more risk factors. Medical providers as well as mental health providers need to be aware of these risks and need to screen for them. For adults with SB, their attitude toward their SB and their satisfaction with their family functioning are most strongly correlated with depressive symptoms (Bellin, et al., 2010). Thus, one role of the mental health provider is to help the individual with SB find positive meaning in their disability. This can be done through cognitive behavioral approaches that work to identify and change maladaptive cognitions and beliefs (Neely-Barnes & Dia, 2008; Brislin, 2008). Therapists can also utilize emotion-focused interventions when elements are out of the individual’s control (Stubberud, et al., 2014). As family functioning also plays a role, taking a systems approach and providing interventions that improve family functioning can also be helpful.

Another area in which mental health providers may be able to play a key role is in the acquisition and encouragement of social skills development. Therapist led social skills groups have been shown to facilitate the development of social skills in youth with SB Essner et al. (2014). Social skills development is important as those who have increased social skills are more likely to fit in with peers, and those who demonstrate better social adjustment in middle school have more intimate relationships in adulthood (Murray et al., 2014). In addition, using behavioral activation techniques to encourage participation in camps (Ridosh et al. 2011) and sports (Groff & Kleiber, 2001) can foster the sense of self-competence and adaptation skills development. Participation in groups also allows for the development and maintenance of social support networks which are crucial in maintaining healthy psyches and identities (Antle et al., 2009; DiCianno et al., 2015; Kinavey, 2007; Van Daalen-Smith, 2006; Shields et al., 2008).

Medical Providers
Often the pediatric population with spina bifida receive medical care in interdisciplinary and coordinated care settings (Liptak, et al., 2015). However, these types of settings often are not available for adults with SB, which leaves them without specialty care. As adolescents age they often take more responsibility in the management of care tasks such as catheterization and skin checks (Psihogios, Kolbuck, & Holmbeck, 2015). Perhaps because they are not skilled in these tasks, or because they do not fully understand the implications of not doing them, many youth enter the adult healthcare system with preventable secondary issues (Wagner, et al., 2015). Due to the complexity of spina bifida and the fact that more and more people with SB are living into adulthood there is a need for more adult SB specialty providers.

There are several tangible strategies medical providers can utilize to aid the transition to adult healthcare. First, they are encouraged to listen to what the caregiver and the individual with SB are bringing into the room (Green, Darling, & Wilbers, 2016). They should involve the youth in decision making to the extent appropriate (Michaud, Suris, & Viner, 2004) so that youth with SB are learning how to make medical decisions from an early age. Providers also need to encourage teens to learn self-management (Michaud et al., 2004; Ridosh et al., 2011). Finally, pediatric providers can work collaboratively with adult providers to aid youth in transition to adult healthcare by making referrals to appropriate providers.

**All Providers**

Lastly all providers can advocate for change nonspecific, do you mean “changes as mentioned above”? as well as work on changing the many attitudinal barriers that people with SB face on a daily basis. Providers can eliminate physical environmental barriers by ensuring that their facilities meet ADA codes for accessibility. They can create training opportunities for professionals on issues of SB and how best to serve those with SB. They can also stay aware of their own biases and issues of counter transference when working with those who have SB.
Being aware of attitudes and creating accessible facilities and programs further ensure that people with SB have access to the variety of healthcare services they need.

**Training Program Standards**

According to Council for Accreditation of Counseling and Related Educational Programs, in 2017 the Council on Rehabilitation Education and the Council for Accreditation of Counseling and Related Educational Programs merged. This widely affects master’s level training programs for mental health clinicians. As part of the merger the two councils are working together to ensure that disability related issues are part of the eight core competency areas of program curriculum in accredited programs. This change will bring awareness of disability and disability issues to future mental health and rehabilitation counselors and better prepare them to work with people who have disabilities. However, for programs accredited by the American Psychological Association (APA), there are no such training guidelines (American Psychological Association). Thus issues of disability are often omitted from accredited doctoral training programs.

Division 22, Rehabilitation Psychology, of the APA is committed to “psychological aspects of disability and rehabilitation, to educate the public on issues related to disability and rehabilitation, and to develop high standards and practices for professional psychologists who work in this field” (American Psychological Association, Division 22). Therefore, one remedy could be that the APA work with Division 22 to implement changes that incorporate issues of disability throughout the nine competency areas. Incorporating disability throughout the training curriculum would greatly help in closing the gap between self-perceived competency and knowledge, and actual competency and knowledge, as purposed by Strike et al. (2004) and it would better prepare future psychologists for working with people who have disabilities.
Limitations

This work provides a base of understanding of the complexities of disability identity development for someone with SB, but it is not without its limitations. The study design of “thematic analysis” was limited by the availability of resources, since the body of existing literature was much smaller and less robust than anticipated. This limited the depth to which the nine identified themes could be developed. Much of the existing literature lacked direct quotes from those with SB, such that the themes were developed through the eyes of the researchers rather than the individuals living with SB. In addition, there was not access to a second coder to cross-reference coding results, therefore the development of themes was potentially limited.

Another limitation is that despite that the Multilevel Model of Identity Content in Context model is developmental and purposes that identify development occurs throughout lifespan, the research on adults with spina bifida is limited in that most studies focus on youth and young adults. This may be because until more recently people with more severe forms of spina bifida did not reach adulthood. Hydrocephalus, a common co-morbidity of spina bifida did not become easily treatable until the Wade–Dahl–Till (WDT) valve was invented in 1962 (Buis & Mandl, 2011). Other medical and surgical techniques to treat a tethered spinal cord, which occurs in 11-27% of those with SB, or scoliosis, which occurs in 52% of people with SB, (Thomson & Segal, 2010) also have become more widely utilized and perfected over the recent decades. These conditions, left untreated, can cause life-threatening medical complications. As those with spina bifida more frequently survive and thrive into middle and late adulthood, it will be crucial to continue to ask questions and learn from their experiences.

This study was further limited by the inability to access original study results. Despite contacting several researchers, this author was not able to review their original results due to IRB regulations. In addition, despite efforts from this author to contact original authors, some were
unable to be located. This additional information may have deepened themes in providing additional quotes and other information that was not published in the articles reviewed for this work. In the original conceptualization of this research the hope was to include all physical congenital disabilities. However, there were very few articles available pertaining to other conditions, leading to the conclusion that work on how identity is developed for people with physical disabilities has been understudied. Thus, the influence these themes have on identity development had to be inferred by this author as the research reviewed did not directly speak to how they influence the process. To do this the author used the Model of Identity Content in Context model proposed by Galliher et al. (2017). Though this model has not been proven valid or reliable as of yet, of the available models of identity development it was the most complex and accounts for the variety of inflectional factors that shape identity.

Limitations identified in the works reviewed also impacted the results of this current work. Issues with participants such as flawed sampling strategy, low sample sizes, high dropout rates, and lack of diversity were commonly listed as limitations (Liptak et al. 2015; Kelly et al., 2011; Holmbeck et al., 2003; Stubberud, 2017; Stubberud & Riemer, 2011; Kelly et al., 2011; Bellin et al., 2010; Davis et al., 2006; Ong, Norshireen, & Chandran, 2011; Ridosh et al., 2011; Jandasek et al., 2009; Friedman et al., 2009; Murray et al., 2014; Essner et al., 2014; Berrya et al., 2013; Lennon et al., 2015; Bloemen et al., 2015). Problems with methodology were reported quite often in these studies, and included issues related to study design, statistical analysis, research biases, and the use of self-report (Kelly et al, 2011; Holmbeck et al., 2003; Stubberud & Riemer, 2011; Warschausky et al., 2017; Bellin & Rice, 2009; Devine et al, 2011; Kelly et al., 2011; Stubberud et al., 2015; Bellin et al., 2010; Buran, et al., 2004; Davis et al., 2006; Holmbeck et al., 2003; Ong et al., 2011; Ridosh et al., 2011; Jandasek et al., 2009; Friedman et al., 2009; Murray et al., 2014; Essner et al., 2014; Lennon et al., 2015; Bloemen et al., 2015). A
variety of issues with assessment and measurement tools were reported as limitations (Liptak et al., 2015; Kelly et al., 2011; Stubberud & Riemer, 2011; Kelly et al., 2011; Ong et al., 2011; Murray et al., 2014; Essner et al., 2014). Finally, issues with interpreting the results, such as a lack of normative data with which to compare, resulting issues with generalizability were reported as limitations (Devine et al., 2011; Bellin et al., 2010; Buran, et al., 2004; Holmbeck et al., 2003; Jandasek et al., 2009; Shields et al., 2008; Essner et al., 2014; Lennon et al., 2015; Bloemen et al., 2015).

**Recommendations for Further Research**

Much research is needed to further understand the role of a congenital disability like SB in identity development. This current work could be expanded on in several ways. First, since it is known that youth with SB are about two years behind in their psychosocial development, future research on identity or psychosocial development should focus on people with SB in their early 20s. Second, a better understanding of the process of identity development needs to be developed. Models like Model of Identity Content in Context need to be validated through future studies. This will allow helping professionals, such as doctors and mental health specialists, develop best practice strategies so that they can provide consistent and quality services to this population. Currently, Dr. Holmbeck is continuing to collect longitudinal data on people with SB who are now in their 20s and even 30s (personal communication, April 20, 2018). This sort of research will be crucial in better understanding the identity development process for those with SB, as well as what can be done to better support a healthy identity development in this population.
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doi:10.1037/Hea0000050


APPENDIX A

Erikson, 1984
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APPENDIX B

Bronfenbrenner’s Ecological Systems Theory
Bronfenbrenner’s Ecological Theory

Chronosystem

Macrosystem

Exosystem

Mesosystem

Microsystem

Family
School
Peers
Religious Affiliation
Workplace

Overarching beliefs and values

Dimension of Time

APPENDIX C

Multilevel Model of Identity Content In Context
Aspects of broader cultural and historical context

Everyday Experiences / Micro Content / Behavioral Episodes
APPENDIX D

Multilevel Model of Identity Content In Context With Themes
Impact of Others: Societal and Political

Employment

Intersecting Domains

Sexuality

Sexuality

Psychosocial

Psychosocial

Psychological and Mental Health

Physical Health

Family Systems

Psychosocial

Transition

Everyday Experiences / Micro Content / Behavioral Episodes
APPENDIX E

Results
Table 1 Results Table

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<td>Transition</td>
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</table>

Figure 1 Pie Chart of Results
APPENDIX F

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