

Disability Identity: The Impact of Disability Type for Individuals with Disabilities

by

Angela L. Hall

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Approved by

Rebecca Curtis, Chair, Associate Professor of Special Education, Rehabilitation and Counseling
Nicholas Derzis, Associate Clinical Professor of Special Education, Rehabilitation and
Counseling
Jill Meyer, Associate Professor of Special Education, Rehabilitation and Counseling
Margaret Shippen, Professor of Special Education, Rehabilitation and Counseling

Abstract

Disability identity development is a fairly recent and unique phenomenon in the academic literature that shapes an individual's way of seeing him or herself, their bodies, their ways of interacting with the world and the way one adapts and responds to his or her disability. This phenomenon of disability identity development has thus far been studied primarily through qualitative methods that focus on the lived experience of individuals. Few quantitative studies exist that attempt to investigate external variables that account for or hinder the development of a person's disability identity. This study attempts to replicate and extend the study by Darling and Heckert (2010) that investigates the impact age has on disability identity development but instead focuses on the variables of disability type: congenital versus acquired, and the impact disability type may have on one's disability identity. By exploring these outside variables and the impact they may have on disability identity in a quantitative way, interventions and therapies could be more appropriately tailored and timed to allow for maximal benefits for the person with the disability. Rehabilitation professionals are on the frontlines in helping individuals with disabilities and are often the connection to the broader disability community. Through quantitative studies that examine external variables such as age, like the Darling and Heckert study (2010), and disability type, like this study, rehabilitation professionals should have a better understanding of the psychological process of disability identity to better meet the needs of their clients in a more positive and affirming way.

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CHAPTER 1. INTRODUCTION

Theoretical Framework for the Study

People with disabilities make up a significant portion of the world's population. The World Health Organization's (WHO, 2018) report on disability and health states that over a billion people or about 15 percent of the world's population lives with some form of disability. Of those living with a disability, between 110 million and 190 million adults have significant difficulties in functioning (WHO, 2018). In addition to these numbers, the report also affirms that rates of disability are increasing due to population aging and increases in chronic health conditions, among other causes. Consequently, people with disabilities have less access to healthcare services and therefore experience unmet healthcare needs (WHO, 2018). Even though so many people are affected by disability, until recently, most of the disability literature regarded it as a form of deviance from the ability and appearance norms of Western society (Darling, 2013). However, as Darling points out, during the past several decades, newer views have reconceptualized disability as a normal form of human variation, much like race or gender (p. 12). The present overarching question then becomes how have the identities of the population of people with disabilities been affected by the views of others in society?

Much of the early theory suggests that the self-conceptions of people with disabilities were overwhelmingly negative and stigmatized (Smart, 2009). Sociologist Erving Goffman's seminal work entitled *Stigma: Notes on the Management of a Spoiled Identity* (1963) is a prime example. Goffman believed that individuals with disabilities needed to learn techniques to

minimize their differences in order to be accepted into mainstream society. More recently, the concept of a spoiled identity has been increasingly challenged and questioned. However, few empirical studies have attempted to directly measure the identities of people with disabilities in today's society (Darling, 2013).

Most identity theorists are in agreement that societal stigma can and does threaten self-esteem, but more recent theories posit that sense of self is both fluid and adaptive and is constructed from a variety of unique sources and individual experiences (Crocker & Major, 1989). Much of the existing literature that links stigma to self-esteem is based on the work of Charles Horton Cooley (1964). Cooley suggested that self-definitions derive from the definitions that we encounter when we interact with others (p. 19). The theory asserts that positive definitions will be reflected in a positive sense of self and that negative definitions will have the opposite effect. Subsequently, stigmatization would be expected to result in negative self-definitions.

In addition to individuals interacting with groups, a large part of self-concept is also based on social group identity. Socio/psychological research grounded in social identity theory (SIT) (Hogg & Abrams, 1988; Tajfel, 1979; Turner et al., 1987) and later social categorization theory (SCT) (Turner & Oakes, 1989), contends that people who are members of groups that are socially stigmatized and devalued, as is the case with people with disabilities, have a more difficult time positively integrating that stigmatizing aspect of identity (i.e., the disability-related difference) into the overall sense of self. SIT also indicates that for members of stigmatized or devalued groups, a cohesive and collective group identity becomes salient (present and activated) only to the degree that people relate themselves strongly and positively with the stigmatized group (Tajfel & Turner, 1979). Because the attribute of "disability" has been historically

devalued and consistently viewed as pathologizing by the Medical Model of Disability in most cultures, development and integration of a disability identity has lagged behind other minority group-based identities such as racial and gender minorities (Mpofu & Harley, 2006; Putnam, 2005; Smart, 2009).

Since the Disability Rights Movement began in the 1960s and 70s, many people with disabilities have become empowered (Darling, 2013). The latest theories suggest a link between identity politics and a more positive definition of the “disabled” [sic] self (Anspach, 1979; Britt & Heise, 2000). Swain and French (2000) introduced the concept of disability pride in their paper on a newer, more positive model of disability referred to as the affirmation model. It is essentially a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for people with disabilities grounded in the benefits of a lifestyle and the life experiences of having an impairment or disability. This view has arisen in direct opposition to the dominant personal tragedy model of disability and impairment grounded in the medical model of disability, and builds on the societal construction of disability that underlies the social model (Swain & French, 2000).

Statement of the Research Problem

A recurrent theme found in the existing scholarly literature regarding identity, especially in Western societies, is the emphasis of a positively distinct, yet socially connected sense of self (Brewer, 1991). This ideal balance can be especially difficult for people with socially stigmatizing identities who have, or are believed to have, an attribute that marks them as different from the majority (Major & O'Brien, 2005). Examples of common socially devalued identities found in the literature include ethnic and racial minorities, gender minorities (including transgender individuals) and people with disabilities (Darling & Heckert, 2010; Jagose, 1996;

Mpofu & Harley, 2006). Even in 2018, the civil rights issues of equality and exclusion continue to exist for these socially devalued groups but for the purposes of this proposed study, the research will focus specifically on people with disabilities. For individuals with disabilities, exclusion is prolific and socially constructed and includes a lack of inclusion into mainstream society that is fueled by stigma, prejudice and discrimination; a lack of empowerment, including making personal choices as a person living in a democratic society; real work for real pay; and finally, the chance to connect and collaborate with those without disabilities in a socially inclusive setting (Martin, 2001; Olkin, 1999). Because of advances in medical technology, individuals with physical disabilities are living longer and are faced not only with the common challenges associated with human existence in a modern society, they must also confront the added complications of living with a disability (Smart, 2009). These differences, or as in the case of this study, these disabilities, are viewed negatively and are undesirable in most Western cultures. This socially marginalized existence often leads to external and internal devaluation of that aspect of self. A positive and healthy disability identity that integrates the disability-related difference into the overall sense-of-self in a constructive and meaningful way has the potential to combat societal stigma and devaluation (Shakespeare, 1996); inform rehabilitation practitioners regarding adaptation to disability (Smart, 2009); and, improve overall quality of life through inclusion in mainstream society primarily through meaningful employment opportunities (Putnam, 2005).

This research study partially replicated and extended the Darling and Heckert (2010) study regarding the impact age had on disability identity but instead focused specifically on the impact disability type had on disability identity development which included disability pride, feelings of exclusion and dissatisfaction, and affirmation of either the medical or social model of

disability. The relationship between disability identity and disability acquisition has been thus far unexplored in the empirical literature. Disability identity and age has been considered by Darling and Heckert (2010) and disability identity and age of onset has been studied by Hahn and Belt (2004). However, additional studies that focus on other variables like congenital versus acquired disabilities and how they impact disability identity are needed to a) demonstrate the power of choice and self-determination, b) to inform policy regarding disability rights, c) to inform rehabilitation practitioners about the differences in adaptation of the two groups, d) combat stigma and devaluation, and e) create opportunities for inclusion in mainstream society primarily through meaningful employment opportunities. Therefore, the focus of this study is the lack of information in the academic literature regarding the influence that disability type may have on disability identity development.

Purpose of the Study

The purpose of this group design study was to partially replicate and extend the study by Darling and Heckert (2010) that investigated age in relation to disability identity. In addition to age, other demographic variables were examined including gender, employment status, ethnicity, marital status, geographic location, and level of education. Descriptive variables such as nature of disability, level of independence, social inclusion, and specifically, disability type (e.g., acquired or congenital) and the impact they have on disability identity were also explored. Disability identity was measured by the Questionnaire on Disability Identity and Opportunity (QDIO) developed by Darling and Heckert (2010) using the constructs of a) feelings of pride versus shame, b) feelings of exclusion and dissatisfaction, c) affirmation of the medical model of disability, and d) affirmation of the social model of disability. The QDIO solicited individuals with disabilities' self-report of their attitudes and beliefs about their disability including

questions regarding *identity*, *model*, *role* and *access* to opportunities for integration into mainstream society such as meaningful employment and integration into the disability community in the form of positive group association.

In reference to the QDIO, Darling (2013) states that *identity* refers to the empirically verifiable aspect of the self-concept that arises through social interactions. In the case of individuals with disabilities, two major disability-related identities have received attention in the literature: shame and pride (Darling, 2013). Shame presumably develops in response to a stigmatizing society and pride has begun to develop out of the Disability Rights' Movement and those activists with disabilities who have come to reject societal devaluation (Putnam, 2005). *Model* refers to a perspective related to a social condition such as "disability." Those who affirm the medical model see disability as a form of illness and view people with disabilities as sick, in need of rehabilitation and a cure. This model has been typically associated with the sick role (Parsons, 1951). The sick role focuses on individual action rather than on social change. Those who ascribe to a social model see a need for social change in the form of physical changes to the environment, as well as attitudinal changes away from stigma and toward acceptance (Darling, 2013). *Role* refers to the disability-related behaviors in which people with disabilities engage. Darling (2010) posits that role choices are closely related to opportunities. In turn, *access* to opportunities are associated with one's status in society (e.g. valued roles and devalued roles) (Wolfensberger, 1982). For example, due to a historically devalued societal status, people with disabilities may not have had the opportunity for exposure to the social model of disability. Consequently, people with disabilities who have only had the opportunity for exposure to the medical model may play the "sick role" because they are unaware of other disability-related identity options (Darling, 2013). When broken down in these terms, it is easy to see how one's

disability identity is shaped through the interaction of these concepts. Therefore, the purpose of this study is to examine how disability type (congenital or acquired) interacts with these concepts to influence one's overall sense of self.

Research Questions

The following research questions were developed for this study:

1. What are the demographic variables of this sample?
2. Are there significant mean differences in reported feelings of disability pride for individuals with acquired disabilities versus individuals with congenital disabilities?
3. Are there significant mean differences in reported feelings of exclusion and dissatisfaction for individuals with acquired disabilities versus individuals with congenital disabilities?
4. Are there significant mean differences in affirmation of the medical model of disability for individuals with acquired disabilities versus individuals with congenital disabilities?
5. Are there significant mean differences in affirmation of the social model of disability for individuals with acquired disabilities versus individuals with congenital disabilities?

Statement of Hypotheses

The following null hypotheses were developed for this study:

The first null hypothesis addressed the second research question.

Ho₁: There are no significant mean differences between individuals with congenital disabilities versus those with acquired disabilities on reported feelings of disability pride.

The second null hypothesis addressed the third research question.

Ho₂: There are no significant mean differences between individuals with congenital disabilities versus those with acquired disabilities on reported feelings of exclusion.

The third null hypothesis addressed the fourth research question.

Ho₃: There are no significant mean differences between individuals with congenital disabilities versus those with acquired disabilities and affirmation of the medical model of disability.

The fourth null hypothesis addressed the fifth research question.

Ho₄: There are no significant mean differences between individuals with congenital disabilities versus those with acquired disabilities and affirmation of the social model of disability.

Definition of Terms

Activism is the policy or action of using vigorous campaigning to bring about political or social change (Merriam-Webster's Collegiate Dictionary, 2018).

Disability Identity is a cultural-developmental phenomenon by which an individual with a disability incorporates into his or her self-definition his or her own disability-related difference and regards that difference as a resource for participation in normative activities of his or her society (Mpofu & Harley, 2006).

Disability Type refers to whether the disability is congenital (i.e., born with the disability) or acquired during the life course (Smart, 2009).

Identity Politics is politics in which groups of people having a particular racial, religious, ethnic, social, or cultural identity tend to promote their own specific interests or concerns without regard to the interests or concerns of any larger political group (Merriam-Webster's Collegiate Dictionary, 2018).

Independence, as it is used in this study, is related to the State of Alabama's Independent Living Centers' (SAIL) criteria for services and refers to an individual with a disability's level of

autonomous functioning regarding activities of daily living. In other words, how much assistance does the individual require with activities of daily living? One of the major eligibility requirements for SAIL services is that the disability must limit the individual's ability to maintain *independence* (ADRS, 2018).

Medical Model of Disability categorizes individuals' disabilities into medical diagnoses and considers the definition, treatment and pathology of the disabling condition to lie solely within the person who has the disability. The medical model does not consider outside constructs or influences (Smart & Smart, 2006).

Social Model of Disability considers context and environment in relation to the disability label. Social influences such as prejudice and discrimination that are found in the broader society are considered more of an obstacle than medical pathology or functional limitations (Smart & Smart, 2006).

Urban, as it is used in this study, refers to the region surrounding a large city and can refer to towns, cities, and suburbs (National Geographic Society, 2012).

Limitations of the Study

This study was limited to the extent that the QDIO instrument captured participants' perceptions of disability pride versus shame, exclusion/dissatisfaction versus inclusion/satisfaction and affirmation of either the medical or social model of disability. Also, because the QDIO is self-report, the results are limited to the extent that participants were honest in answering the instrument questions. An additional limitation of the study is that those with congenital disabilities who participated in this study (n=24), 22 of the 24 had sensory disabilities (i.e., deaf or hard of hearing).

Delimitations of the Study

The scope of this study was limited to people with disabilities who qualify for and utilize the services provided by the three Independent Living Centers in the state of Alabama and people with disabilities who have traumatic brain injuries (TBI) and participate in the Alabama Head Injury Foundation's peer support groups.

Assumptions

The following assumptions applied to this study:

1. Participants responded honestly to the questionnaire.
2. Participants were confident in their ability to answer questions about themselves regarding demographic information as well as beliefs, attitudes and experiences regarding their disability.

Need for the Study

Research in this area would have important practical applications. In addition to increasing scholarly knowledge about the population of people with disabilities in general, the results of the QDIO could be used by practitioners to learn more about the identity formation of individuals with disabilities and the impact disability type may have on perceptions of identity, as well as contribute information that could be used to develop a more accurate model of disability identity development (Lyew, Mueller & Samples, 2017). As well as a better understanding of how disability is incorporated into the overall sense of self, it is also possible that this research will provide a more in-depth and accurate picture of disability identity and orientation and the external influences that may have a significant impact. Therefore, a better understanding of disability identity development may result in interventions to promote those orientations to disability that are associated with better quality of life outcomes including

meaningful employment and a reduction in stigmatization and devaluation. Finally, policy makers need to be aware of the diversity of orientations toward disability when developing legislation or programs for this population. Social policy can increase or decrease opportunities for social inclusion for individuals with disabilities (Putnam, 2005).

Significance of the Study

Even with the social justice movements of the 60s and 70s, including the Disability Rights' Movement and the Independent Living Movement, as well as the resulting anti-discrimination federal legislation of the Americans with Disabilities Act (1990), civil rights issues of equality and exclusion continue to exist for socially devalued groups such as ethnic minorities and people with disabilities (Martin, 2001). Studies that investigate the impact that external variables like age, age of onset, socioeconomic status, employment, education, living status, and disability type have on minority identity development have the potential to provide a greater understanding of these minority groups by the mainstream majority. This enhanced understanding of both collective and individual minority identity development, specifically disability identity development, has the potential to reduce fear and stigma related to the socially constructed category of "disability" and would provide more opportunities for inclusion into mainstream society. Previous research has shown that more opportunities for inclusion of people with disabilities also leads to additional opportunities for meaningful employment, as well as financial and emotional independence (Darling & Heckert, 2010; Putnam, 2005). This study also has the potential to inform rehabilitation practitioners' knowledge of the differences in adaptation styles of individuals with acquired disabilities versus those with congenital disabilities.

CHAPTER 2. REVIEW OF THE LITERATURE

Introduction

Chapter I provided the background information for this study, statement of the research problem, significance and purpose of the study, research questions, statement of hypotheses, study limitations and assumptions. Chapter II provides a review of literature and research on the evolution of identity theories, disability identity theories, as well as studies and models that illustrate these theoretical frameworks.

In recent years, scholars working in an array of social science and humanities disciplines have taken an intense interest in questions concerning *identity*. Within sociology, for example, we find the concept of identity at the center of debates in almost every major subfield. Much new research has been devoted to the *identity politics* of race, gender, and sexuality (Abes, Jones & McEwen, 2007; Mpofu & Harley, 2006; Putnam, 2005). Identity plays a major role in work on nationalism and ethnic conflicts (Deng 1995; Horowitz 1985; Laitin, 1999; Smith 1991). In international relations, the idea of *state identity* is at the heart of constructivist critique and analyses of states' sovereignty (Biersteker & Weber, 1996; Katzenstein 1996; Lapid & Kratochwil, 1996; Wendt, 1992, 1999). In political and social theory, questions of identity are included in numerous arguments on gender, sexuality, nationality, ethnicity, and culture (Connolly, 1991; Kymlicka 1995; Miller 1995; Taylor, 1989; Young, 1990).

In spite of this increased interest by the academic community in identity, the concept itself still remains difficult to define, especially in terms of the modern uses of the word

(Gleason, 1983). The present idea of identity is a fairly recent social construct and dictionary definitions are confusing at best and do not go into the detail required by modern academic standards to understand the concept as it is used in scholarly discourse and empirical research.

After an extensive review of the existing social science literature, it is apparent that academic users of the word “identity” take for granted the readers’ understanding of the concept. Some examples include Hogg and Abrams (1988, p. 2): Identity is “people’s concepts of who they are and how they relate to others”; Deng (1995, p. 1): “Identity is used in this book to describe the way individuals and groups define themselves and are defined by others on the basis of race, ethnicity, religion, language, and culture,”; Jenkins (1996, p. 4): Identity “refers to the ways in which individuals and collectivities are distinguished in their social relations with other individuals and collectivities,”; Wendt (1992, p. 397): Identities are “relatively stable, role-specific understandings and expectations about self,”; Katzenstein (1996, p. 59): “The term [identity] (by convention) references mutually constructed and evolving images of self and other,”; and finally Taylor (1989, p. 344): “My identity is defined by the commitments and identifications which provide the frame or horizon within which I can try to determine from case to case what is good, or valuable, or what ought to be done, or what I endorse or oppose.”

The range of definitions of identity are varied and complex. This can be attributed in part to the multiple disciplines that identity is of interest. Different research traditions are influenced by a wide variety of theoretical orientations including role theory, Eriksonian psychology, social identity theory, social constructionism, and minority models of identity formation, to name a few. As this research has evolved, these various theoretical approaches have developed somewhat different definitions regarding the notion of identity. However, despite the diversity, they are closely related enough that they evoke a sense of recognition to the common underlying

concept of identity. This, in part, can be attributed to the term identity's strong roots in ordinary language but this everyday use can also be a major reason for the need to alleviate the ambiguity and define identity as thoroughly and entirely as possible.

Three themes of identity meaning and usage emerged from the existing literature regarding identity formation theory. The first usage to emerge as thematic is the notion of individual identity development and is usually derived from within a cultural context. Calhoun (1994) states that when this meaning is employed, no distinction is drawn between culture and ethnicity, for example. The second theme that appears repeatedly in the literature is when identity refers to common identification with a collective group or social category as in Social Identity Theory and Self-Categorization Theory (Tajfel, 1982). Snow and Oliver (1995) examine identity in relation to social movements and how this collective identification with a group creates a common culture among members. Finally, the third theme that emerged from the literature regarding the meaning of identity is when it refers to the self-composed meanings that individuals attach to the multiple roles or identities they typically play in highly differentiated, modern societies. This usage is supported theoretically by Wolfensberger's (1983) theory regarding individual identity formation and the direct influence of societal roles on this process. He states that these societal roles and the meanings attached to them by cultural and societal practices are directly related to one's self-esteem and feelings of acceptance by others. In order to understand the academic research ramifications of these common, yet fundamentally distinctive, definitions of identity found in the literature, it is important to first examine the evolution of identity theory.

Evolution of Identity Theory

Individual Identity Development

Individualism is a core value of many Western societies. In the United States, for example, the premise that people should be free to explore their individuality and to express their true selves is fundamental to the culture (Bellah, Madsen, Sullivan, Swindler & Tipton, 1985; Spindler & Spindler, 1990). American literature and film repeatedly portray those who are different as heroic and virtuous (Kim & Markus, 1999). Often, being true to oneself is portrayed as an act of courage; a thing that must be pursued, even in the face of group pressure. The hero is rarely the one who plays by the rules or willingly submits to others' authority. More often the hero is the nonconformist, even the outsider in many instances. Conversely, authority figures, groups, and traditional societal values are often portrayed as oppressive and as forces working against the fulfillment of individual potential (Sampson, 1988).

The sociologist George Herbert Mead (1934) was the first to develop a framework from which to understand the concept of identity. His research and resulting framework asserted a formula: "society shapes self shapes social behavior" (p. 6). Identity theory began by a) attempting to specify and make researchable the concepts of *self* and *society* within Mead's formula, b) to organize these explanations of specified behaviors that could be tested empirically, and finally c) to answer the question of why identity salience may change over time (Stryker & Burke, 2000). Stryker and Burke (2000) define *identity salience* as the identity(s) that is most relevant or active at any given time, depending upon the contextual environment and specific circumstances. These questions led to the development of theory concerning ways in which people are tied into the social structure and the consequences of those ties as they relate to identities as in the case of social construction theory (Omni & Winant, 1994) and social identity

theory (Tajfel, 1974). Mead's "social behavior" evolved into "role choice behavior" which seeks to answer the question of ... When in a given situation, with behavioral options that are aligned with two or more sets of role expectations attached to respective positions in social networks, why do individuals choose one course of action over others? (Stryker, 2007).

Acceptance of Mead's "self reflects society" implies that self, like society, is multifaceted. Thus, identity theory adopts the notion that people have as many selves or identities as groups with which they interact. Therefore, identity refers to each group-based self the person possesses (Stryker & Burke, 2000; Tajfel, 1985). In other words, people have as many identities as distinct networks of relationships in which they occupy positions or play roles. In identity theory usage, *social roles* are expectations attached to positions occupied in networks of relationships. Thus, identities are also internalized role expectations that are organized within the self in a salience hierarchy that reflects the existing societal hierarchy (Stryker & Burke, 2000; Wolfensberger, 1983). As such, identities are cognitive bases for defining situations and they increase sensitivity and receptivity to certain cues for behavior.

In his hierarchy of needs, Maslow (1968) placed the need to form loving social bonds immediately above the more primitive drives such as hunger, for instance, but below the need for esteem. Consistent with Maslow's Hierarchy of Needs is Sternberg's (1986) and Hazan and Shaver's (1994) findings that forming social bonds is characterized by positive emotions and when social bonds break down, it is usually accompanied by pain and protest. The preponderance of the literature also shows that to be ignored or ostracized, even by strangers, is a highly aversive experience and those who feel rejected or lonely are more likely to experience physical or mental pathology than those whose social relationship needs are fulfilled (Hamachek, 1992; Williams, 2001). This inner drive for intimacy with others is universal and strongest under

conditions of adversity or threat, supporting the notion that belonging may have its evolutionary advantages as well (Rofe, 1984).

Identity as commitments. According to Mead (1934) and subsequent identity theory scholars, people tend to live their lives in relatively small, specialized networks of social relationships. *Commitment* refers to the degree to which persons' relationships to others in their networks depend on the possession of a particular role or identity. Commitment is measurable by the costs of losing meaningful relationships to others should the identity cease to exist (Stryker & Burke, 2000). The theory hypothesized that the *salience*, or the immediate importance of an identity, reflected commitment to the role relationships requiring that identity. These specifications arrived at by identity theorists exemplifies Mead's formula in that commitment shapes identity salience, shapes role choice behavior (Stryker & Burke, 2000).

One component of commitment is the number of others to whom one is connected by possessing a particular identity (Stryker, 1980). This aspect of commitment reflects density of ties, a characteristic of the social structure in which identity is embedded. Connectedness increases the salience of the identity, making it more likely that the identity will be activated in a given situation. For example, people occupying densely connected positions and holding related roles will have identities associated with those positions and roles that are more salient. A doctor or a clergyman may fall into these densely connected, more salient positions within the culture and their role behaviors usually reflect these strong commitments to the social structural expectations in which they operate (Wolfensberger, 1983).

Identity integration. Commitment level implies some degree of integration. *Integration* is defined as incorporating or combining into a whole, and is a recurring theme in human development theory (Gill, 1997). The concept of integration appears in some form in most

classic theories of personality development and is associated with positive outcomes, such as maturity, cognitive comfort and emotional health. Gill (1997) briefly describes the familiar process of integration with regard to personality and identity development as when the child or adult goes through a life crisis(es) that is plagued with psychological disorganization and distress; with proper support and exploration, the individual begins to make sense of these conflicting feelings and perceptions; and, finally, those seemingly incongruent elements synthesize into a newer, stronger, more discernable level of identity organization that allows for improved relationships with the social environment.

Much of the tension that is created by this process of integration can be attributed to the polarity of separation and unity that is found across theories of personality development (Gill, 1997). Sometimes the crisis can take place entirely within the individual as in the case of psychoanalytic theory and Freud's (1957) divisions of the human psyche: the superego, the id, and the ego. According to early psychoanalytic theory, these three divisions of the psyche are often in conflict with one another. The superego can be thought of as the moral task master, the id as the impulse network, and the ego as the realistic self (Freud, 1957; Gill, 1997).

Other times, as Rogers (1951) pointed out in his person-centered approach to psychotherapy, the focus is on the relationship between the individual and the social environment. He emphasized the importance of congruence between the internal self and the totality of external experiences in mediating self-esteem and psychological health. He also emphasized the importance of congruence between the internal self-image and the ideal self or the way one wishes to appear to others (Gill, 1997). Rogers (1951) states that failure to integrate opposing forces within the individual and/or social domains signals an arrest in the individuals' journey toward advanced psychological functioning.

Based on her observations of infants, Mahler (1968) theorized that humans are born lacking a sense of distinctness from surrounding objects within their environment, including human caregivers. According to Mahler, newborns experience external and internal stimuli in a confused atmosphere of sensations and are unable to sort out their own actions from those of others. Through interaction with the environment and with parental nurturing, over time, the infant learns where he or she ends and others begin, a process Mahler calls *separation-individuation* (Gill, 1997). Mahler posits that a primitive identity forms when the infant can unify or *integrate* his or her own experience into a continuous sense of self, separate from the existence and actions of others.

Erik Erikson (1965) believed that psychosocial identities are constructed throughout the lifespan. By “psychosocial,” he meant an interplay between the inner most personal, emotional life (psyche), and the outer, more public, social and environmental circumstances (social). Erikson believed that as one ages, one passes through eight distinct stages of development. He thought that each stage was defined by a specific conflict between a pair of opposing impulses or behaviors. The resolution (or inability to resolve) these conflicts affects personality and identity formation in either a positive or a negative way. It was Erikson (1959) who first gave identity two distinct, and in his estimation, opposing forces, of the personal realm and the social realm. This information is portrayed in Table 1.

Table 1

Erik Erickson's Psychosocial Stages of Identity Development

Stages	Crisis	Favorable Outcome	Unfavorable Outcome
Childhood			
1 st year of life	<i>Trust vs. Mistrust</i>	Faith in the environment and future events	Suspicion, fear of future events
2nd year	<i>Autonomy vs. Doubt</i>	A sense of self-control and adequacy	Feelings of shame and self-doubt
3rd through 5th years	<i>Initiative vs. Guilt</i>	Ability to be a "self-starter," to initiate one's own activities	A sense of guilt and inadequacy to be on one's own
6th year to puberty	<i>Industry vs. Inferiority</i>	Ability to learn how things work, to understand and organize	A sense of inferiority at understanding and organizing
Transition Years			
Adolescence	<i>Identity vs. Confusion</i>	Seeing oneself as a unique and integrated person	Confusion over who and what one really is
Adulthood			
Early Adulthood	<i>Intimacy vs. Isolation</i>	Ability to make commitments to others, to love	Inability to form affectionate relationships
Middle Age	<i>Generativity vs. Self-absorption</i>	Concern for family and society in general	Concern only for self-one's own well-being and prosperity
Aging years	<i>Integrity vs. Despair</i>	A sense of integrity and fulfillment; willingness to face death	Dissatisfaction with life; despair over prospect of death

Identity status. Much of the existing research on identity development is based on Marcia's (1966) identity status model which takes a departure from the Eriksonian developmental model of polarizing outcomes of only positive or negative (Bosma & Kunnen, 2001). According to Marcia's status model, individuals can be classified into one of four statuses on the basis of the process variables "crisis" (later "exploration") and "commitment" in various content domains. According to Marcia (1966), the *foreclosed status* is characterized by strong commitments without exploration, the *diffused status* is characterized by absence of commitment and absence of exploration, the *moratorium status*; by absence of commitments but active exploration, and *achievement status*; by strong commitments that have been chosen and integrated into the identity after a process of exploration. Table 2 illustrates Marcia's theory of identity.

Table 2

Marcia's Identity Status Model

		Has a crisis been experienced?	
		Yes	No
Has a commitment been made?	Yes	Identity achievement	Foreclosure
	No	Moratorium	Identity diffusion

Identity salience. The basic principle that priming a salient group identity leads to enhancement of self and other group members has been supported in numerous studies on salience (e.g., Haslam, Oakes, Reynolds & Turner, 1999; Oakes, Haslam, & Turner, 1994; Shih, Pittinsky & Ambady, 1999; Stryker & Serpe, 1994), including studies that attempted to answer

the questions about the origins of differential salient identities in self-structures and why identity salience may change over time (Stryker, 1968; Wells & Stryker, 1988). In turn, these questions led to the development of theory concerning ways in which people are tied into social structure and the consequences of these ties for their identities. The theory then asserted a link between identity salience and behavioral ties to roles underlying the identities. Theorists argue that expectations attached to roles were internalized then acted out (Burke & Reitzes, 1981). This last link solidified the conceptualization of identities as cognitive schemas by which people define situations, then behave according to the established role expectations or those salient to one's identity (Stryker & Serpe, 1994).

Still, a clearer understanding of the way in which salient identities produced particular behaviors was required. The solution was based on the symbolic interactionist ideas that identities are self-meanings and that self-meanings develop in the context of role and counter-role meanings (Abes, Jones & McEwen, 2007; Burke, 1997; Burke & Tully, 1977). Burke and Reitzes (1981) and Abes, Jones and McEwen (2007) proposed that the link between identity salience and behavior exists in the meanings they share. Thus, identity theory is able to consider something as seemingly inconsequential as everyday expectations through identity salience for a person occupying the most mundane of societal roles, such as the consumption of certain materials, preparing food, earning a living, and buying goods and services (Burke, 1997).

Integration of the two strands of early identity theory is the foundation for the modern view of identity formation and how this blending of self and society shapes the meaning given to roles and commitments (Stryker & Burke, 2000). One strand emphasizes the social structural sources of identity and their relationship and the other focuses on the internal, cognitive identity processes (Stryker & Burke, 2000). Stryker and Burke (2000) describe how the two meet and

the resulting behavior is an outward expression of the valuation (or devaluation) of that particular salient identity that is played out through interaction with others.

One can see the complimentary nature of structural and cognitive identity theory by examining how these two emphases fit together. The concept of identity salience implies that people are more likely to define situations they enter, or which they find themselves, in ways that make a highly salient identity relevant; this process enables them to enact that identity. In other words, situations where identity is questioned or threatened and must be asserted makes that facet of identity highly cognitively salient, as well as responsive and relevant to the structural environment. Stryker and Burke (2000) refer to this as *identity confirmation process*. If the identity confirmation process is successful, the salience of the identity will be reinforced. If the process is unsuccessful, the salience of the identity is likely diminished, perhaps considerably.

Social Role Valorization

To elaborate further on the links between the two parts of identity theory, examination of existing social structure theory is relevant and necessary. Identity theory has generally focused on role identities of individuals and later, groups. *Roles* are external and linked to social positions within the social structure. Identity is first internal, consisting of internalized meanings and expectations associated with an individual role (Burke & Tully, 1977). In addition to the roles themselves, each role or set of roles, is embedded in one or more of a variety of groups that provide context for meanings and expectations associated with the role. Stryker and Serpe (1982) give examples of groups that provide contextual role meanings as networks, organizations, classes, unions, and other social units that have a collective set of established and accepted ideals and standards for group membership. This structure or connectedness between

roles and groupings provides the first level of social structures' impact on identities (Tajfel, 1982).

Some aspects of social structures are problematic from the viewpoint of commitment to a particular role relationship in that a gap between self-relevant perceptions and societal identity standards exists. People are typically embedded in multiple role relationships in multiple groups and they hold multiple identities (Reitzes & Mutran, 1994; Thoits, 1983; Wiley, 1991). These multiple roles may serve to reinforce one another but, as in the case of Freud's ego divisions, more often, they do not. When they do not, they introduce identity competition or conflicts that complicate the reciprocal relationships between commitments, identity salience, identity standards, and self-relevant perceptions (Stryker, 2000). At the heart of this paradox rests a basic conflict between two fundamental human motivations: the need to experience group belonging and the need to feel like a differentiated and distinct individual (Hornsey & Jetten, 2004).

Staying with the theme of individuals fulfilling societal roles in the process of identity formation, the notion that best supports this premise is Wolfensberger's (1983) Social Role Valorization (SRV) theory. SRV states that social roles dominate people's lives and individuals perceive themselves and each other in terms of these respective roles. The value attributed to various social roles tends to instrumentally affect the behaviors directed toward individuals, depending upon the value or devalue of that particular role as it exists within the social hierarchy. Those individuals in valued roles tend to be treated well and those in devalued roles tend to be treated poorly (Wolfensberger, 1983). Wolfensberger's (1983) most current revision of SRV discusses those roles that are stereotypically devalued in most Western societies, the possible results of this societal role devaluation, and how SRV can be utilized to, theoretically,

“upgrade” some of the more devalued roles, thereby elevating the value of those individuals who typically occupy those roles.

Not surprisingly, at the top of Wolfensberger’s (1983) list of devalued roles are those individuals who are impaired in some way, including those with sensory impairments, physical, psychological and/or cognitive disabilities. The next most devalued individuals on his list are those whose behavior is considered socially deviant, including individuals who are excessively hyperactive, are unorthodox in their sexual orientation, and those who use alcohol and/or drugs. Moving down the devaluation list, next are those who possess extreme physical characteristics such as excessive tallness or shortness; individuals who rebel against the social order; the poor; the illiterate or those with seemingly nothing to contribute to the intellectual growth of the society; and, finally; those individuals who are unassimilated into the culture such as religious minorities and racial and ethnic minorities (Wolfensberger, 1983).

Typical negative life experiences of devalued individuals. When people are devalued by others, there is a high probability that this devaluation will impact them in a negative way (Wolfensberger, 1983). Wolfensberger (1983) gives an extensive description of the adverse ways that devaluation may affect a person’s healthy identity development. He lists these as 18 typical negative life experiences and refers to them as *wounds* of devalued people. The first of these wounds includes people becoming devalued because they have a disability, whereas others may acquire a disability as a result of having been devalued. For example, as a result of living in poverty, poor nutrition, unsafe living conditions, little to no access to specialized health care, or even the likelihood of being assaulted, are all possible and likely outcomes as a direct result of a low socioeconomic status (Wolfensberger, 1983).

The second wound Wolfensberger (1983) lists has the same comorbid relationship as the first; many people become devalued because their disability is functionally limiting and many others become functionally [disabled] (e.g., illiteracy) as a result of being devalued. In other words, these individuals are not seen as significant enough by the existing society to teach them basic skills such as literacy. An example of this can be taken from pre-Civil War America and the way African American slaves were treated on plantations by the White cultural majority; as not having enough intrinsic value to warrant being educated to read and write, therefore perpetuating cultural and ethnic isolation and control.

The third wound that Wolfensberger describes is once an individual is devalued (as in the cases of wounds 1 and 2), they are at extreme risk of getting relegated to a low social status and are often looked down upon by the societal majority. It is very difficult to elevate one's social status once it has been systematically devalued and the devaluation has been internalized by the individual. Wounds 1–3 often lead to a systematic series of rejections not only from society but also from community, family, friends, and often, by human service workers of the devalued individual (Wolfensberger, 1983). Wounds 4–8 discuss the ways in which these devalued individuals face systematic rejection in most quality of life (QOL) domains with negative role assignments, value judgments, societal “scapegoating”, and segregation. Wounds 9–18 address devalued individuals' loss of control over their lives; discontinuity with places and physical objects, including possessions; discontinuity of social relationships, as in the case of natural relationships like those with family, friends, and community members that either never develop or get withdrawn or severed; deindividualization; impoverishment of economic status and experiences; the cut off from knowledge of and participation in value systems such as religion and spirituality; “life-wasting” in or by the service programs that are supposed to help them; and

finally Wolfensberger states individuals who typically hold devalued roles are at high risk for being brutalized and violated (1983).

Group Identity Development

The concept of group identity development emphasizes the contextual and environmental influences that interact with the individual. Sherif (1966) states “whenever individuals belonging to one group interact, collectively or individually, with another group or its members *in terms of their group identification*, we have an instance of intergroup behavior” (p. 12). In order to understand what Sherif and other identity theorists mean by intergroup behavior, the underlying concepts of “groups”, “group identification” and the consequences of group membership such as stigma, stereotyping, and prejudice need to be defined and explained.

According to Tajfel (1982), a group can be defined on the basis of either external or internal criteria. *External criteria* are the outside designations or labels that larger society often assigns such as bank clerks, hospital patients, or members of a particular trade union. *Internal criteria* are those of *group identification* and depend upon two necessary components: a cognitive sense of awareness of membership by the individual and an evaluative one in the sense that this individual awareness of membership has some value connotations attached. Although unnecessary for group existence, the third component is the emotional investment by the individual members in the aforementioned awareness and evaluative components. Therefore, there can be no intergroup behavior unless there is also some external consensus that the group exists, just as there can be no intergroup behavior if those individuals considered members have no external awareness of common group membership nor the value connotations associated with it. In other words, for group identification to exist, there must be at least some combination of external recognition combined with an individual’s awareness of internal association, including

meaning attachment (Abes & Kasch, 2007; Hornsey & Jetten, 2004; Tajfel, 1982). These external labels and internal meaning attachments are the basis for group identities and help to define both individual and group stereotypes that often result in stigmatization and stereotyping (Tajfel, 1982).

Stigmatization. According to Thornicroft, Rose, Kassam and Sartorius (2007), *stigma* can be thought of as an overarching term that contains three elements: problems of knowledge (*ignorance*), problems of attitudes (*prejudice*), and problems of behavior (*discrimination*). When the majority group reacts with prejudice in rejecting a minority group, negative thoughts, as well as negative emotions such as anxiety, anger, resentment, hostility, distaste, and disgust often occur (Thornicroft et al., 2007). They elaborate further with the supposition that prejudice may depict discrimination much more strongly and accurately than do stereotypes. According to Goffman (1963), stigma is an attribute that extensively discredits an individual, reducing him or her “from a whole and usual person to a tainted, discounted one” (p. 3). Crocker, Major and Steele (1998) proposed that stigmatization occurs when a person possesses (or is believed to possess) “some attribute or characteristic that conveys a social identity that is devalued in a particular social context” (p. 505). These three definitions share the notion that those who are stigmatized have (or are believed to have) a characteristic that marks them as different and this difference is viewed negatively and devalued by others. Stigmatizing “marks” may be controllable or uncontrollable, visible or invisible, and linked to appearance, behavior, or group membership (Major & O’Brien, 2005). Most importantly, stigma does not reside within the person who is stigmatized but rather in the social context. In other words, stigma is context and relationship specific (Major & O’Brien, 2005).

Most stigma scholars regard stigma as a socially constructed phenomenon, i.e. a label attached by society, and past studies on stigma point to variability across time and cultures as to which attributes, behaviors or groups have been the most stigmatized (Crocker et al., 1998). However, evolutionary scholars' evidence points to a commonality across cultures and history of stigmatized traits that include communal perceptions of a) a poor partner for social exchange, b) the probability of a parasitic infection, and c) a member of an outgroup that can be exploited for ingroup gains (Kurzban & Leary, 2001; Neuberg et al., 2000). These categories of exclusion line up very closely with Goffman's (1963) proposed categories of stigmatizing features that include blemishes of individual character, abominations of the body, and tribal stigma.

Crocker and Major (1989) hypothesized that all of these methods of social exclusion: stereotyping, stigma and prejudice, often lead to threats to both the personal and collective identity and can also lead to attributional ambiguity or uncertainty as to whether outcomes are due to one's personal identity or one's social identity. Steele (1997) proposed that cultural knowledge that one belongs to a devalued or marginalized group leads to social identity threat or a threat to that aspect of the self that is derived from group membership. Steele and Aronson (1995) theorized that negative self-relevant group stereotypes can lead to stereotype threat, a situationally based fear that one will be judged on the basis of attempts by others to confirm the attributes attached to the stereotype.

Stallybrass (1977) defines *stereotype* as...

An over-simplified mental image of (usually) some category of person, institution or event which is shared, in essential features, by large numbers of people ... stereotypes are commonly, but not necessarily, accompanied by prejudice, i.e. by a favorable or unfavorable predisposition toward any member of the category in question. (p. 601)

The behavior of certain individuals often becomes relevant to the stereotype of their group because they are representatives of a category which has a preexisting social significance enmeshed with preexisting value connotations. Attention-focusing on one individual as representative of an entire group becomes important for stereotyping mainly when it happens in the context of these preexisting evaluative social differentiations and also when it is determined by them. Outside of this context, there is still no evidence that attention-focusing on individuals who are in some ways “different” is a primary condition of the process of stereotyping (Tajfel, 1982).

Effects on intergroup behavior. When all of the aforementioned conditions are met for group membership, individuals become representations of the larger group, especially in the social realm. Therefore, the interactions between ingroups (the group/s one belongs to) and outgroups (those other groups in existence that one does not belong to) have a definite mitigating effect on intergroup behaviors and perceptions (Tajfel, 1982). The most easily recognizable example of the effect of group identity on behavior can be found by examining the behaviors of different ethnic groups who interact. In a cross-cultural study of *ethnocentrism*, or the belief in the inherent superiority of one’s own ethnic group or culture, by Levine and Campbell (1972) of 30 different ethnic groups in East Africa, they found that between group differences that were emphasized were both flexible and context dependent. Brewer (2001) states that this flexibility permits individuals to mobilize different group identities for different purposes. Therefore, different group identities became salient depending upon circumstance, environment, and purpose (Levine & Campbell, 1972). A similar study conducted by Jaspars and Warnaen (1982) in Jakarta, India where many different ethnic groups live in close proximity to one another, found that groups do not necessarily evaluate outgroups more negatively than their own group.

They did find, however, that ingroups often have a more positive view of themselves than other groups have of them. They related their findings to the processes of social identity and social comparison which will be discussed in more detail later in this paper (Jaspars & Warnaen, 1982).

Western studies of the effects group identity have on behavior in children such as those conducted by Pushkin and Veness (1973) and Katz and Zalk (1978), conclude that at a very early age, children from underprivileged groups tended to reflect the social consensus about the status and the image of their group by adopting outgroup identifications and preferences, while the majority children clearly showed ethnocentric attitudes. These studies demonstrate the intense sensitivity, by both the majority and minority children, to the surrounding social climate of intergroup differences and evaluations (Tajfel, 1982). According to these results, the minority ingroup may form a basis of positive self-image if it managed to preserve a system of positive evaluations about its mode of life, social, and cultural characteristics. However, when the group also suffers from a lower social status, positive social identity may come into conflict with the negative evaluations from other external groups whenever comparisons of the higher status groups become salient (Katz, 1973). This process of devaluation, both from the minority ingroup itself and from other, external groups, often results in self-deprecation by the members of the minority group (Tajfel, 1982).

Power and legitimacy. An important factor related to group identity and member behavior is its perceived legitimacy and power over other groups. The only other experimental evidence about power legitimacy and discrimination has been provided by Hornsey, Spears, Cremers, and Hogg (2003), who operationalized power legitimacy in terms of whether the distribution of subgroup representatives in a superordinate power structure reflected accurately (or inaccurately) the population distribution. Results showed that groups discriminated more

when power differentials were illegitimate than when they were legitimate. However, results from these studies also showed that power did not affect discrimination (Hornsey et al., 2003). Ellemers and Barreto (2001), like Hornsey et al. (2003), showed that illegitimacy of status leads to higher group cohesion. According to these findings, it is reasonable to assume that power illegitimacy, acting upon group cohesion, would serve to enhance group members' perceptions of the interdependent relationship between group membership and positive outcomes associated with group membership.

Hornsey et al. (2003) conceptualized the power of a group as the degree of control exerted over its own fate and the fate of other groups. According to Ng (1982), the presence of usable power is precisely what makes intergroup discrimination possible. Testing the effects of arbitrary power differentials in minimal groups, Sachdev and Bourhis (1991) found that members of low power groups discriminated less than those of equal power groups, which in turn, were less discriminatory than members of high or absolute power groups. Sachdev and Bourhis (1991) also argue that usable power is essential to discriminate, but it does not directly contribute to members' positive social identity. However, the evidence collected by Sachdev and Bourhis (1991) and more recently by Amiot and Bourhis (2005) pertains to restricted conditions of ascribed power differentials. It is therefore worthwhile to investigate how power differentials affect discrimination when power is obtained in other ways, for example, by accomplishment (Rubini et al., 2007). In doing so, Rubini et al. (2007) showed that, as predicted, power differentials between groups produced higher discrimination than power equality. Also, members of legitimate high power groups discriminated more than members of illegitimate high power groups, while members of legitimate low power groups were less discriminatory than members of illegitimate low power groups. Unexpectedly, participants in

the illegitimate equal power condition showed higher ingroup favoritism and employed the maximum differentiation strategy more than participants in the legitimate equal power condition (Rubini, et al., 2007).

Through his extensive research on group behavior, Tajfel (1982) concludes that members of groups which have repeatedly found themselves at the bottom of the social pyramid with little to no power sometimes display the phenomenon of self-hate. This self-deprecating behavior as it relates to social comparisons with the outside world often leads to a variety of internal conflicts, some of which achieve their resolution in seeking and finding responsibility for the social discrepancies in an external locus of control, i.e. the social system at large as in Social Identity Theory (SIT), Social Comparison Theory (SCT) and Social Construction Theory (Hogg & Terry, 2000; Tajfel, 1974; Weinrich, 1979).

At odds with this internalization of group stereotypes by lower status groups resulting in self-hate and self-deprecating behavior, are the ego-defensive perspective theories developed to explain the high levels of individual and collective self-esteem frequently observed among members of socially disadvantaged groups (Crocker & Major, 1989; Rosenberg & Simmons, 1975; Tajfel & Turner, 1986). According to this perspective, individuals and groups are highly motivated to enhance and protect their individual and collective self-esteem and engage in a wide variety of “self-serving” and “group-serving” cognitive and behavioral strategies in the service of these goals. Ego-defensive theories predict that, when plausible, members of socially disadvantaged groups will attribute their poor outcomes to external factors such as prejudice and discrimination, rather than to internal factors, because of the self-esteem protection external attribution provides (Allport, 1954; Goffman, 1963).

Intergroup conflict and competition. Status and power are the major components that surround intergroup distinction and competition (Tajfel, 1982). Social status often equates to power in most cultures and societies, both ancient and modern. In other words, individuals and groups with a higher social status usually possess more power than those whose social status is lower on the social hierarchy. When status confers power, it is the power differential that causes the most intergroup conflicts (Ng, 1978). The subject of status and its role in group power differentials is validated in an extensive field study conducted by Van Kippenberg (1978) using engineering students from two Dutch institutions of higher learning of differing status and prestige. Among his results, “status” was evaluated more highly by the lower status group. Van Kippenberg attributes this phenomenon to the interest of the higher status group to minimize the importance of status power differentials, while at the same time, it may be in the interest of the lower status group to magnify the power differential that status infers (p. 12). This fundamental conflict reflects the fact that these differentials are often not accepted as legitimate. In fact, most intergroup conflicts are based on the illegitimacy of these power differentials. This refusal by minority groups to blindly accept the embedded cultural norm that a higher social status automatically equals power over others is an example of what Tajfel (1982) found as the ingroup’s higher perception of their status than outgroups.

Directly related to these effects of the perceived illegitimacy of social power differentials is a series of studies by Katz et al. (1973) and Katz and Glass (1979) on the ambivalence of the higher status group (the white majority) toward the stigmatized (racial minorities). The conflict stems from the discrepancy between accepted values and the treatment of racial minorities. The results showed that information about African Americans and Latinos lead to a polarization of reactions toward them by members of the white majority. The authors attribute this finding to

the threat to the self-esteem of the stigmatized group the attitudinal ambivalence of the White majority causes (Katz & Glass, 1979). When self-esteem is threatened on a group level, individual identities are often sacrificed for the survival and strengthening of the group identity. A stronger and more unified group identity then becomes salient and usually serves to increase group cohesion and group investment in the conflict. In other words, abuse of power differentials by the majority often creates resolve among affected minority groups and also creates a more defined group identity.

Social Identity Theory

Tajfel (1972) first introduced the concept of social identity as the individual's knowledge that she belongs to certain social groups together with some emotional and value attachments that come along with this group membership. The early concept of social identity involved considerations such as stereotyping and prejudice that are inherent with intergroup membership and according to Tajfel (1972), almost necessary to define one's place in the existing social hierarchy. He goes on to explain how social identity has evolved into the consideration of how self is conceptualized in intergroup contexts, or how a system of self-categorizations creates and defines an individuals' *own* place in society (Tajfel, 1972, 1974). Motivated by an underlying need for self-esteem, social identity rests on intergroup social comparisons that seek to confirm or establish in-group membership and create distinctiveness between the ingroup and the outgroup (Turner, 1975). To explain the nature of the relationships between groups including concepts such as status, stability, permeability, and legitimacy, and the way these concepts influence a positive social identity, Tajfel and Turner (1979) retained this emphasis in their research and development of the extension of Social Identity Theory to include the concept of social categories.

Self-Categorization Theory

The emphasis of social identity as part of the self-concept was explored more fully by Turner and his colleagues (Turner, 1982, 1985; Turner et al., 1987) and this inclusion of social categories in the research evolved into the formal development of Self-Categorization Theory (SCT), which specifies in detail how social categorization produces prototype-based depersonalization of self and others, therefore generating social identity phenomena. At about this same time, Hogg and Abrams (1988) integrated and grounded intergroup, self-conceptual, and motivational emphases into Tajfel's and Turner's existing framework of social identity and social categorization theory.

SCT's focus on *prototypes*, or the conceptualized role and the typical traits that accompany it, allows for some important theoretical developments regarding social categories and the extension of SIT (Hogg & Terry, 2000; Tajfel & Turner, 1979). For example, when group membership is salient (present and activated), cognition is guided by the various prototypes that exist within the group. This allows group members the ability to distinguish themselves from other group members, and also gives them a sense of how well they match the prototype. Some individuals are perceived to be more "prototypical" than others (Hogg & Hains, 1996). This theoretical process allows SIT theorists to better explain social identity-based, intragroup processes such as cohesion and social attraction, deviance and overachievement, and leadership and intragroup structure differentials (Hogg & Terry, 2000).

Social categories have two distinct features. First, they are defined by implicit and/or explicit rules of membership. These membership rules are driven by the individuals who are assigned or not assigned to the category. Second, social categories are understood in terms of sets of characteristics. Beliefs, desires, moral commitments, or physical attributes thought

typical of members of a category, or behaviors expected of said members in certain situations define the parameters of the group characteristics. This is true in the case of social roles such as mother, professor or student. This is considered the content of the social category that the membership rules have dictated as acceptable or unacceptable. When referring to one's identity, generally speaking, is to refer to the social category in which the person has placed himself (or has been placed by others) (Berger & Luckmann, 1966; Hogg & Abrams, 1988; Jenkins, 1996; Searle, 1995; Tajfel, 1982). Fearon (1999) states that in many cases found in the literature, "social category" might be a clearer and more exact term than "identity." While this identity-as-social-category captures much of the scholarly research conducted regarding identity, it does not apply to Erikson's aforementioned concept of personal identity. In other words, this social category definition is still too broad and oversimplified for the purposes of this study. In an effort to further explain this concept of identity, one must turn to constructivist scholarship and the idea that individuals possess multiple identities and this practice of categorization is a socially constructed phenomenon (Fearon, 1999).

Multiple and Intersecting Identities

Social constructionism. Weber (1998) identified social constructionism as a common theme within the academic literature that explores the relationships among race, class, gender, and sexuality. Social constructionism challenges the medical model position that presumes these categories are grounded in biological processes (Abes, Jones & McEwen, 2007). Conversely, social constructionism considers identity to be socially, historically, politically, and culturally constructed at both the institutional and individual levels (Omi & Winant, 1994). The meaning of social identities cannot be fully captured as they change with evolving contexts and relationships by the medical model position of biological processes alone (Omi & Winant, 1994).

Feminist conceptualizations of intersectionality. Much of the study on multiple identities in the literature grew out of Black feminist scholarship that challenged feminism's Eurocentric assumptions (Hooks, 1984; Smith, 1982). This feminist literature introduced a framework of intersectionality that recognized how socially constructed identities are experienced simultaneously, not hierarchically (McCann & Kim, 2013). Collins (1990) termed this framework a "matrix of domination" and explained that viewing relationships from an intersecting perspective expands the analysis from merely describing the similarities and differences to distinguishing these systems of oppression and focuses on how they interconnect (p. 222).

Autobiographical narratives from two feminist scholars, Lorde (1984) and Anzaldua (1999), illustrated a "new consciousness" (Anzaldua, pp. 101) associated with integrating multiple identity dimensions within a matrix of domination rather than a hierarchical structure. Lorde, an African American lesbian feminist socialist mother of two and a member of an interracial couple, explained that her "fullest concentration of energy is available ... only when I integrate all the parts of who I am ... without the restrictions of externally imposed definition" (pp. 120–121). Anzaldua, a Mexican American lesbian and a mestiza discussed her ability to bring together multiple identities into a new, integrated identity where "the self has added a third element which is greater than the sum of its severed parts. That element is a new consciousness" (pp. 101–102). To fully embrace individual experiences, it is necessary to explore differences within each aspect of identity as each is influenced by the simultaneous experience of the other dimensions (McCann & Kim, 2013).

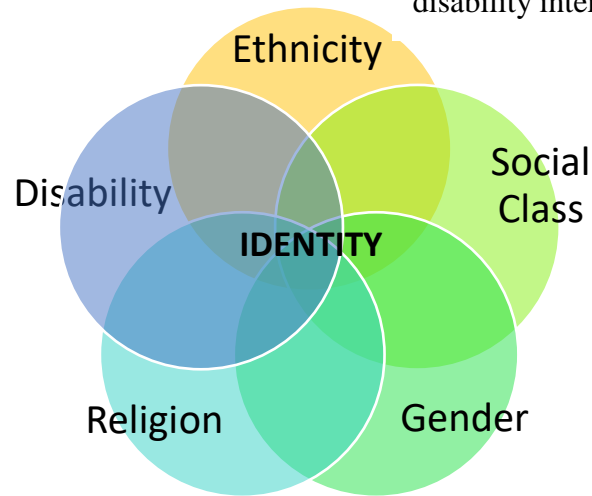
Postmodernist conceptualizations of intersectionality. Postmodernists stress differences between and within groups, including race, class, gender, and sexual orientation. A

postmodern conceptualization of difference suggests that this construct cannot be easily “dismantled” into “oppositional predicates” and is neither this nor that; but rather this *and* that (Kearney, 1995, p. 110). A postmodern critique of identity challenges the stability of identity categories. These postmodern scholars assert that categories are insufficient because differences within those categories cause them to have “multiple and contradictory meanings” (Fuss, 1990, p. 98).

Relevant to the reconceptualization of the model of multiple identities is the postmodern perspective of queer theory, which suspends the categories of lesbian, gay, bisexual, masculine, and feminine (Tierney & Dilley, 1998). Components of queer theory challenge traditional identity categories based on the assumption that identity is performed and therefore unstable (Butler, 1993) and comprised of fluid differences rather than a unified, singular identity (Fuss, 1990). Fuss suggests that the failure to study identity as difference implies a false unity that overlooks variations that exist within identity categories such as race and class (p. 22).

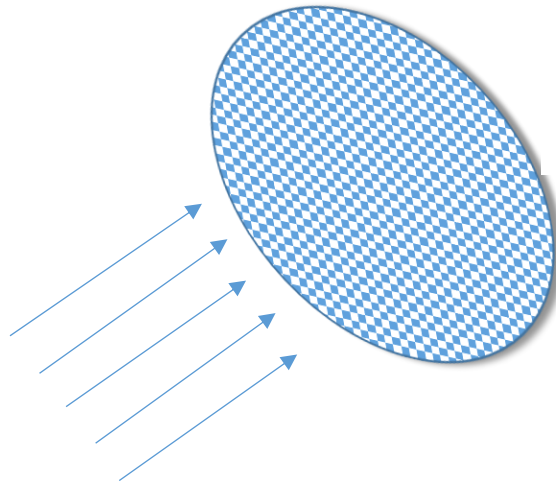
Model of multiple dimensions of identity. Jones and McEwen’s (2007) model of multiple dimensions of identity offers a conceptual depiction of relationships among college students’ socially constructed identity dimensions, recognizing that each dimension cannot be fully understood in isolation. The model is based on the work of Reynolds and Pope (1991) and Deaux (1993), and is also founded on the results of grounded theory research with women college students by Jones (1997). This model is depicted as Figure 1.

Self-Perceptions of Multiple, Intersecting aspects of identity such as ethnicity, social class, and disability interact with one another.



Meaning-Making Filter: Depending on complexity, contextual influences pass through to different degrees.

Contextual Influences such as peers, family, social norms, stereotypes, etc. pass through the meaning-making filter and impact all aspects of identity.



Adapted from: Abes, E. S., Jones, S. R., & McEwen, M. K. (2007). Reconceptualizing the model of multiple dimensions of identity: The role of meaning-making capacity in the construction of multiple identities. *Journal of College Student Development*, 48(1), 1–22.

Figure 1. Model of Multiple Intersecting Identity Formation

The model of multiple dimensions of identity describes the dynamic construction of identity and the influence of changing contexts on the relative salience of multiple identity dimensions, such as race, sexual orientation, culture, and social class. The model portrays identity dimensions as intersecting rings around a core, signifying how no one dimension can be understood without considering its relationship to other dimensions (Abes, Jones & McEwen, 2007). At the center of the model is a core sense of self, comprising “valued personal attributes and characteristics” (Abes, Jones & McEwen, 2007, p. 383). Surrounding the core and identity dimensions is the context in which a person experiences life, such as family, sociocultural conditions, and current experiences. The salience of each identity dimensions to the core is fluid and depends on contextual influences (Abes, Jones & McEwen, 2007).

Constructivist-developmental theory and multiple identities. Kegan (1994) integrates intrapersonal, cognitive, and interpersonal domains of development as part of a single, integrated mental activity and describes the interrelated development of each domain from simple to complex. Kegan’s (1994) integrated theory consists of five orders of consciousness representing increasingly complex meaning-making structures which are sets of assumptions that determine how an individual perceives and organizes life experiences (p. 14). King and Baxter-Magolda (2005) developed a conceptual framework for intercultural maturity grounded in the integration of cognitive, interpersonal, and intrapersonal development. The intrapersonal dimension of their framework presents a relationship between Kegan’s (1994) orders of consciousness and theories of social identity development (King & Baxter-Magolda, 2005).

Abes and Jones (2004) simultaneously considered Kegan’s (1994) constructivist-developmental theory and the model of multiple dimensions of identity in a study exploring how lesbian college students perceived their sexual orientation identity and its interaction with other

dimensions of identity, such as race, religion, social class, and gender. Results of Abes and Jones's study suggested that meaning-making capacity served as a filter through which contextual factors are interpreted prior to influencing self-perceptions of sexual orientation identity and its relationship with other identity dimensions. How context influenced these perceptions depended on the complexity of the meaning-making filter. Participants with complex meaning-making capacity were able, more so than those without less developed capacity, to filter contextual influences, such as family background, peer culture, social norms, and stereotypes, and determine how context influenced their identity. Complex meaning-making also facilitated the ease with which sexual orientation was integrated or peacefully co-existed with other dimensions of identity (Abes & Jones, 2004).

The results of Abes and Jones's (2004) study suggest that incorporating meaning-making capacity into the model would more thoroughly depict the relationship between context and salience (and self-perceptions) of identity dimensions, as well as the relationship between social identities and the core of identity. This reconceptualized, integrated model portrays in two dimensions the interactive nature of the relationships among components of the identity construction process: context, meaning-making, and identity perceptions. Meaning-making capacity is depicted as a filter in the model and how contextual influences move through this filter depends on the depth and permeability of the filter and is in direct proportion to the person's meaning-making capacity. Regardless of differences in meaning-making, context influences identity perceptions (Abes & Jones, 2004).

Incorporating meaning-making capacity into the model provides a richer portrayal of not only *what* relationships people perceive among their personal and social identities, but also *how* they come to perceive them as they do. By incorporating personal and multiple social identities,

Jones and McEwen's model provides a holistic representation of the intrapersonal domain; with the inclusion of meaning-making capacity, the reconceptualized model provides a holistic representation of the integration of intrapersonal development with cognitive and interpersonal domains. It also provides a lens to understand more clearly how people view themselves and this knowledge allows professionals to more effectively engage in meaningful and individualized partnerships to help them develop a more complex understanding of their identity and the power associated with defining identity for oneself (Abes, Jones & McEwen, 2007). See *Figure 1* above.

Disability Identity Development

People with Disabilities in the US

Having a disability places you in the world's largest minority group (Human Diseases and Conditions Forum, 2018). In addition to the aforementioned WHO statistics for the world population and disability, according to the American Community Survey administered in 2016 by researchers at the University of New Hampshire, the percentage of people with disabilities in the US was 12.8% (Lauer, Coleman & Houtenville, 2018). The results of this survey also showed that as the US population ages, the percentage of people with disabilities increases. In the US in 2016, less than 1.0% of the under 5 years old population had a disability. For those ages 5–17, the rate was 5.6%. For ages 18–64, the rate was 10.6%. For people ages 65 and older, 35.2% had a disability (Lauer, Coleman & Houtenville, 2018). Along with the relationship between age and disability, these survey results also found that in 2016, of the US population with disabilities, over half (51.0%) were people in the working-ages of 18– 64, while 41.4% were 65 and older.

The survey also showed significant disparities in employment rates, median earnings, poverty rates, and health-related issues between those with disabilities versus those without disabilities. There were 35.9% of people with disabilities ages 18–64 living in the community that were employed. The employment percentage was more than double for people without disabilities at 76.6% (Lauer, Coleman & Houtenville, 2018). Employment rates vary by type of disability. Employment percentages were highest for people with hearing disabilities (51.7%) and vision disabilities (43.5%) and lowest for independent living (17.0%) and self-care (15.5%) disabilities. In addition to significant disparities in employment rates between those with disabilities versus those without disabilities, median earnings were also less for those individuals with disabilities. In 2016, the median earnings of people with disabilities ages 16 and over in the US was \$22,047, about two-thirds of the median earnings of people without disabilities, \$32,479 (Lauer, Coleman & Houtenville, 2018). The disparity in the poverty rate in 2016 was higher for individuals with disabilities at 20.9% versus those without disabilities at 13.1%, a difference of about eight percentage points. Finally, the results of the survey showed that people with disabilities had more health-related issues such as smoking and obesity than those without disabilities (Lauer, Coleman, & Houtenville, 2018).

The Disability Rights Movement and Identity Politics

Historically, one term describes the lives of people with disabilities: isolation. As Darling (2013) points out, in the past people with disabilities living at home were commonly geographically isolated from one another. Many did not even attend school. Prior to the passage of the Americans with Disabilities Act (ADA) in 1990, individuals with disabilities were environmentally isolated through architectural barriers such as buildings with stairs and no elevators and inaccessible public transportation. Before advances in technology, people with

disabilities were isolated due to the inability to effectively communicate with mainstream society, much less others with disabilities. Stigma and shame of being different led to social isolation. As a result of these circumstances, the Medical Model of Disability prevailed and many did not realize that other people with disabilities even existed (Smart, 2009). Unlike members of racial and ethnic groups, people with disabilities commonly grew up in households with people without disabilities, so development of a shared identity could not occur until they left home or encountered others like themselves (Darling, 2013).

Once individuals with disabilities realized they were part of a larger group, identity-shaping processes like group identification and group cohesion previously discussed in the literature review section of this paper began to take place (Tajfel, 1974; Tajfel & Turner, 1979). One of the most important catalysts for disability identity development was the Disability Rights' Movement of the 60s and 70s (Putnam, 2005). Among other disability scholars, Darling (2013) contends that an important stimulus for the Disability Rights' Movement was the Civil Rights Movement that began in the 1950s and 60s. African Americans and women provided organizational models on behalf of minority rights. In the 1970s, largely due to these other social justice movements, the Independent Living Movement by individuals with disabilities grew out of a culture of student activism at the University of California at Berkeley. The growth of the movement was further fueled by advances in technology, including media exposes which helped ignite the Deinstitutionalization Movement in the 80s (Darling, 2013). Along with these social justice movements, media exposure, and advances in technology, legislative mandates such as the ADA and the Individuals with Disabilities Education Act (IDEA) in the 90s helped to solidify people with disabilities' identity as a minority group that was no longer isolated (Putnam, 2005).

Unmistakably, identity and activism have been interconnected in the principles of the Disability Rights Movement. Anspach (1979) was one of the first to use the concept of identity politics to refer to social movements that “seek to alter the self-conceptions and societal conceptions of their participants” (p. 765). The Disability Rights Movement was able to identify the source of participants’ problems within the inequitable social structure rather than the participants themselves and challenged prevailing negative views and replaced them with more positive ones. In an empirical study using two samples of people with disabilities by Nario-Redmond and colleagues (2013), results showed that “those who claimed disability as a central aspect of their identity were more likely to value their disability experiences, express community pride, and advocate for social change” (p. 18). By promoting a collective identity, social movements can shape the personal identities of their members, as well as those nonmembers who become aware of the movement’s message (Putnam, 2005). However, as Putnam (2005) points out, the process through which a political disability identity becomes internalized has received little research attention.

Congenital versus Acquired Disabilities

Congenital birth defects are common, costly, and critical conditions that affect one in every 33 babies born in the United States each year; that is about 120,000 annually who are born with a congenital disability (CDC, 2008). According to the Centers for Disease Control and Prevention’s report on congenital birth defects in the US, depending on the severity of the defect and what body part or body system is affected, the expected lifespan of a person with a congenital disability may or may not be affected (2008). Congenital disabilities may be diagnosed before birth through the first year of life. These diagnoses may include physical, developmental, and cognitive disabilities and often lead to chronic conditions that are prevalent

throughout the lifespan. Babies who have congenital birth defects often need special care and interventions to survive and to thrive developmentally. Early intervention is vital to improving outcomes for these babies. However, as previously mentioned, depending on the severity of the diagnosis, interventions and support may be necessary throughout the lifespan (CDC, 2008).

Disabilities also can also be acquired at any time after birth. Other than aging, acquired disabilities commonly arise from accidents, illness, working conditions that expose a person to an unhealthy environment (such as coal miners who breathe in coal dust), or repetitive physical stresses (such as repeated heavy lifting) (Human Diseases and Conditions Forum, 2018). Because of individual identification ambiguity with the minority group of “disability,” solid statistics on acquired disabilities are difficult to find in the academic literature. However, there are indicators and some individuals are more at risk of acquiring a disability than others. For example, poor people are more at risk of acquiring a disability because of lack of access to good nutrition, health care, sanitation, as well as safe living and working conditions. Once this occurs, people face additional barriers to the education, employment, and public services that can help them escape poverty (Human Diseases and Conditions Forum, 2018). Other risk factors include alcohol and drug abuse, diet and nutrition, and obesity (CDC, 2018). People who acquire disabilities later in life have a different experience from those who are born with a disability (Smart, 2009). Whether it is physical or cognitive in nature, these individuals have lost something that has played a part in the development of their identity. People with acquired disabilities tend to go through a grieving process similar to the grieving process for any other major life loss. Their emotions usually follow these stages: grief, denial, anger, depression, living with a “new normal,” and finally, acceptance of the disability (Smart, 2009).

Smart (2009) states that in the cases of congenital disabilities, the families are the ones much more likely to move through the stages of acceptance and adaptation, not necessarily the person with the disability. While at the same time, as an integral part of the person with a disability's immediate environment, the family and friends' dynamic influences the individual's positive or negative response to the disability. Smart (2009) also makes the argument that in cases of congenital disabilities, it is often the mother who internalizes much of the guilt and pain associated with having given birth to an imperfect child. As a result of legitimate medical questions about the mother's health and/or decisions she may have made during the pregnancy, society passes judgment and the mother internalizes these judgments more than other family members because she is biologically responsible for the child's well-being during the pregnancy. The stages' theories are more accurately applied when the disability is acquired. These stages' theories of adaptation are more indicative of the individual response to an acquired disability and is based on grieving and loss theories, specifically, Kubler-Ross's (1969) theory of acceptance of death (Kubler-Ross & Kessler, 2005; Smart, 2009). Nonetheless, Smart (2009) contends that the loss theory (which includes distinct and identifiable stages of grief) is missing two important components when addressing individual response to acquired disability: the impact of stigma and prejudice and the lack of mental preparatory time to prepare for the loss. With regard to impending death, aging and chronic/terminal illness, there is usually a period to prepare emotionally and behaviorally for the loss (Smart, 2009). Conversely, this is not the case with an acquired disability. It is often sudden and traumatic with little to no time to prepare psychologically for the death of the person before the disability. Essentially, the feelings of loss and grieving stem from mourning the loss of the pre-disability identity (Smart, 2009).

History of Disability Identity

Charmaz (1995) and Frank (1993) were among the first to research disability identity. Their research focuses on disability acquisition. Frank (1993) used the illness narratives of many individuals to explain that acquisition of a disability most often leads to a period of critical reflection and subsequent self-change. He suggests that this self-change is necessary to accommodate the changes that come through disability acquisition. Charmaz (1995) addresses disability identity through the daily struggles of individuals with chronic illness. In Charmaz's (1994, 1995) longitudinal study of 55 adults with chronic illness, she noted the difference in acquiring a disability if a person has already achieved identity synthesis as opposed to being in turmoil over one's identity.

Olkin and Pledger (2003) and Darling (2003) also contributed to the early literature regarding disability identity. Their analyses centers around the question, "When do people consider themselves to be persons with disabilities?" Darling (2003) examined the impact of the Disability Rights Movement on disability identities and determined that the identity of at least some individuals with disabilities has changed and that a stigma-based identity model has been replaced by disability pride.

Most studies that focused on disability identity were qualitative in nature and concentrated on individual experiences. Few studies have investigated preventive or predictive variables that account for or impede the development of a person's disability identity. This line of research has the potential to become an important factor when developing effective interventions and therapies for individuals with disabilities. Rehabilitation professionals are often directly involved in helping newly diagnosed and/or injured individuals and are often the only connection to the broader disability community. Therefore, it is imperative that these

professionals have a better understanding of the process of disability identity development in order to better meet the needs of people with disabilities.

Disability Identity Studies

Table 3 includes peer-reviewed quantitative disability identity studies found in the existing academic literature. The author(s), year, and location are in the first column, participants and age range are in the second column, and data collection procedures are located in the third column.

Table 3

Quantitative Studies on Disability Identity

Author(s)/Year/Location	Participants and age (<i>M</i> or range)	Data Collection Procedures
Bjorvatn & Tungodden (2015), Norway	780 participants with hearing or mobility impairments (16.8 years)	Lab experiments
Bogart (2014)/US	226 adults with congenital (36.96 years) and acquired (57.12 years with mobility disabilities)	Online Questionnaire
Bogart (2015)/US	106 adults with multiple sclerosis (58.3 years)	Online survey
Darling & Heckert (2010)/US	388 adults with cognitive, mobility, hearing, speech or cosmetic impairments (18–65+ years)	10 participants for focus group, 388 for questionnaire
Hahn & Belt (2004)/US	156 adults with disabilities (17–73 years)	Survey
Kindermans et al. (2010)/The Netherlands	80 adults with chronic low back pain	Survey
Shattuck et al. (2014)/US	120 adults on the autism spectrum	Survey
Zhang & Haller (2013)/US	359 adults with disabilities (47.31 years)	Online Survey

Individual Disability Identity Development

Throughout this paper, identity formation and development have been discussed in the context of individuals and groups, including the categories of race, class, gender, and sexual orientation. Because identities help people make sense of different and distinct parts of their self-concepts, a self-actualized and healthy identity for people with disabilities should contain relevant content and goals linked to disability (Dunn & Burcaw, 2013). Therefore, the term *disability identity* is defined by Mpofu and Harley (2006) as a cultural-developmental trend whereby an individual with a disability incorporates into his or her self-definition his or her own disability-related difference and regards that difference as a resource for participation in the same activities that people without disabilities participate in in mainstream society. The development of disability identity constructs has lagged behind those for other minority related statuses, such as race and gender. For example, there is at present no widely recognized theory on disability identity development. The lag in the development of theories of disability identity relative to identity development in other minority statuses parallels the historical delay by civic society in recognizing people with disabilities as a minority or culturally distinct group (Mpofu & Harley, 2006).

Constructs do exist that have the capability to be the foundation for a theory of disability identity development (Mpofu & Harley, 2006). These constructs share the following assumptions: a) their disability status would be salient when defining themselves; b) to be self-actualized, including understanding and accepting the psychosocial ramifications of the disability; c) acknowledging a disability identity would lead to a higher awareness of disability-related prejudice and discrimination by those without disabilities; and d) possessing a strong

disability identity would help to recognize and combat disability related stigma (Noonan et al., 2004).

More progress has been made in the development of theories of adaptation or integration of disability than in theories of disability identity development. However, disability identity is not the same as acceptance of disability (Mpofu, 1999). As previously mentioned in this paper, integration is a recurrent theme in classic theories of personality development and Gill (1997) provides a strong foundation for a future model of disability identity development. Gill's (1997) work focused on the importance of integration of self in forming identity and presents a multi-stage, non-linear model for the identity formation of individuals with disabilities. Gill's four aspects of disability identity formation explain the process of integrating the disability aspect, both physical and psychosocial, into the individual's salience hierarchy in a positive way. *Coming to feel we belong* focuses on recognition of oppression; *Coming home* focuses on initial contact with others with disabilities thus the realization that one is not alone; *coming together*, defines the process of integrating one's whole self and abandoning the references to certain body aspects or traits as "good" or "bad"; and finally *coming out* focuses on the external presentation of one's self to the world, or in other words, taking pride in a disability identity.

Group Disability Identity Development

Traditionally, people with disabilities have been denied a group identity by mainstream society through oppression and isolation (Gill, 1997). The lag in the development of theories of disability identity relative to identity development of other minority statuses parallels the historical delay by civic society in recognizing people with disabilities as a minority or culturally different group (Mackelprang & Salsgiver, 2016). Inspired by the civil rights struggle of other minority groups such as African Americans and women, people with disabilities have begun to

define who they are and where their place is in society. According to Gill (1997), inaccessible environments, transportation systems, and poverty are barriers to community organizing and resources. Categorization rooted in the Medical Model of Disability and antiquated social service delivery perpetuates separation and makes group unity difficult (Smart, 2009). Social values that see disability as a fate worse than death discourage individuals with disabilities from seeking out stigmatized peers. This drive for wholeness and definition has resulted in organizations and public policies that safeguard people with disabilities rights as citizens as well as cultural efforts to celebrate differentness as valuable and a source of group strength and identity (Gill, 1997). This journey described by Gill (1997) portrays a growth process that involves at least temporary relinquishment of former attachments (or commitments), redefinition of self, and reconfiguration of relationships to others and society. All of the above-mentioned potential risks and rewards of the process mentioned earlier in this paper that Mahler (1968) refers to as separation-individuation, is the effort by people with disabilities to improve the prospects of integration as a foundation of group identity development.

The first of Gill's (1997) four types of disability identity integration, *coming to feel we belong*, refers to the feelings of social exclusion often reported by people with disabilities. Historically, the first step toward a positive identity development for minority groups in the U.S. has been the assertion of the right to be included in mainstream society (Putnam, 2005). For example, children with disabilities often express the desire to attend community schools with "everyone else," and adults with disabilities talk about equal opportunities for employment. However, just like with other minority group identity development, Gill (1997) affirms that historically, people with disabilities have been viewed as objects of charity and targets of

professional rehabilitation and remediation and this collective societal attitude has trained them to view themselves as excluded from the opportunities and possibilities of a “normal” life.

The Americans with Disabilities’ Act (ADA) (1990) is a prime example of how legislation and policy, although slow at times, can and does affect social change in the U.S. This anti-discriminatory legislation that protects those with disabilities from inequitable practices under the law, has given people with disabilities a sense of equal value and an expectation of societal acceptance and accommodations for their differentness. It also places the blame for “not fitting in” more on the creators of the restrictive environments, roles and occupations, and less on the individuals with disabilities themselves (McCann & Kim, 2013).

Intersecting Disability Identity Development

A healthy disability identity could achieve the same protective balance and enhance the development of positive self-esteem as a healthy racial identity. For example, people with healthy disability identities may be more likely to engage in proactive problem-solving when stereotypes are imposed and their ability to make choices about careers are questioned by those without disabilities (Mpofu & Harley, 2006). According to Mpofu and Harley (2006), *ableism* or the automatic assumption by those without disabilities that those with disabilities cannot perform certain tasks because of their disability (or *type* of disability), is a major barrier for the career development of people with disabilities. A healthy disability identity would be a protective factor for ableism (Mpofu & Harley, 2006).

Constructs within racial identity development models have the potential to help define disability identity development and they share the following assumptions: a) people with disabilities would regard their disability status as salient to defining themselves; b) a person with a disability must accept a disability related identity to achieve superior psychosocial functioning;

c) owning to a disability identity would lead to a greater consciousness of disability-related discrimination, marginalization, and prejudice from having a disability; d) a strong disability identity may be a resource for combating disability-related stigma (Mpofu & Harley, 2006); and, e) disability status may not be the primary lens through which most people with disabilities perceive their personal identities or career options (Batavia & Schriener, 2001).

More progress in the development of theories of acceptance or adaptation to disability has been greater than in theories of disability identity development (Mpofu, Thomas & Chan, 2004). However, disability identity is not the same as acceptance or adaptation to disability. Smart (2008) describes different levels of acceptance to disability and just because a person accepts the disability on some levels does not mean she has accepted all aspects of the disability in all QOL domains. Subsequently, acceptance does not imply transcendence of the disability nor does it automatically include viewing the disability as an asset or a positive aspect of identity (Smart, 2009). For example, a person may accept that they have a disability but that does not necessarily translate into assimilation of the disability into a positive part of that person's identity (Batavia & Schriener, 2001).

A developed disability identity is important for learning about successful career participation with a disability (Mpofu & Harley, 2006). For example, a person with a healthy disability identity development would more readily acquire available knowledge about the functional requirements for certain careers, potential barriers in obtaining certain career goals, and strategies for obtaining their career of choice (Mpofu & Harley, 2006). These proactive strategies are a result of a healthy disability identity and with it, the empowering knowledge of how the social context can and does influence career aspirations. A healthy disability identity would also be an asset for optimal career participation, as it would aid individuals in forging

mutually beneficial partnerships with others with disabilities and proactively co-construct enabling career environments. In other words, it is helpful for proactively creating opportunity structures for achieving one's career goals (Mpofu & Harley, 2006).

Individuals may be at different statuses of racial and disability identity development and their particular career counseling outcomes are a product of the complex interactions between their racial, disability, and other identity statuses (Mpofu & Harley, 2006). Despite civil rights legislation and affirmative action initiatives, rehabilitation professionals must avoid the assumption that African Americans and people with disabilities have access to the same career opportunities and choices that those non-minority groups have. The historical experiences of institutionalized disadvantage, deprivation, and oppression influence the identities of minority groups and their career participation (Mpofu & Harley, 2006).

The queer community's history is in many ways not unlike that of the disability communities' history. Queer individuals have also faced a Biomedical Model approach that their sexuality is inherently pathological and dangerous, at times, even non-existent, and have been viewed as individuals whom the medical world needs to "fix." The disability and queer communities have faced medicalization, simultaneous asexualization and hypersexualization, and institutionalization (Whitney, 2006).

In recent years both the Disability Rights Movement, as well as the Queer Rights Movement, have made progress. Individuals with disabilities are increasingly becoming recognized as adults and as such having the same sexual desires and wishes as other adults. However, many working with individuals with disabilities as well as friends and family often assume heterosexuality. Simultaneously, many in the queer community do not realize the presence of members with disabilities.

Women, in addition to the queer and disability identity, may find themselves facing sexism and limited job opportunities. Additionally, assumptions of asexualization have been particularly strong for women with disabilities. Whitney (2006) then focuses her research on queer women with disabilities and the ways they navigate their identities as disabled [sic] and queer. Many women report a splitting of oneself and rejection by both communities with which they may identify. Feelings of lacking community support that many queer women with disabilities experience can be exhausting, isolating, and lead to internalized ableism and homophobia. Queer women with disabilities often face barriers in coming to terms with their sexual orientation identity that women without disabilities do not. Shakespeare (1999) looked at the word usage in the queer community and concluded that much of the key terminology that is related to feelings of pride and unity may inhibit participation of individuals with disabilities. Phrases such as “lesbian strength” and “voice” inherently, if unintentionally, place value on able-bodied characteristics (Shakespeare, 1999).

Shakespeare’s (1999) research also explored differential identities and identity formation processes for those who acquired a disability after becoming part of the queer community and for those whose disability identity was a foundation of themselves before their queer identity. His results indicated that most individuals’ identity salience is grounded in the *first* identity. For example, if a woman has identified as a part of the lesbian community for ten years and then acquires a disability, she is most likely to state that the lesbian community is her primary support group and central to her identity.

Interactional models appear to be the most logical and practical models to explain the identity formation process of intersecting marginalized identities. Cramer and Gilson (1999) define the interactional models as those which dynamically incorporate aspects of biology,

cognition, and social and historical surroundings without using a fixed linear scale. Furthermore, interactional models posit identity as fluid and dynamic.

Eliason's (1996) model of lesbian identity development is an example of an interactional model that may also well explain disability identity development. Eliason (1996) argued that identity development is a fluid and evolving process and presented a four-component model of identity formation of lesbians that posits the stages of pre-identity, emerging identities, experiences and recognition of oppression, and reevaluation/evolution of identities. While one must begin in the pre-identity stage and does not return to this stage, all of the other three stages can be passed through and returned to numerous times as identity is shaped and reshaped upon new experiences. Eliason's model of lesbian identity development contained similarities to Gill's (1994) model of disability identity formation as well as other minority models of identity development such as racial identity development theory.

Disability Identity Development Models

Models for disability identity development do exist but are few and relatively new to the academic literature. Some of these models represent a stage theory that implies individuals' progress from one stage to the next. Others describe the phases or statuses but do not imply a direct progressive relationship that one specific phase must be passed through before transitioning to the next one. Also of note, not all of these models are based on the same disability identity theoretical tenets. Some of these models were developed with the stages of grief in mind, others were interactional in nature. Table 4 lists existing disability identity models and includes the author, year, and model title in the first column and the major conceptual components in the second column.

Table 4

Models of Disability Identity Development

Model	Concepts
Gill's (1997) Disability Identity Model	Coming to feel we belong Coming home Coming together Coming out
Hahn and Belt's (2004) Disability Identity and Attitudes in Activists	Affirmation of a disability identity Communal attachments
Putnam's (2005) Domains and subdomains of political disability identity	Self-worth Common Cause Pride Discrimination Policy Alternatives Engagement in Political Action
Gibson's (2006) Disability Identity Model	Passive Awareness Realization Acceptance
Darling and Heckert (2010) Questionnaire on Disability Identity and Opportunity	Identity (Pride vs. Shame) Model (Social vs Personal) Role (Activism vs Passivity) Affirmation of Disability
Dunn and Burcaw's (2013) Narrative Accounts of Disability	Communal attachments Self-worth Pride Discrimination Personal meaning
Forber-Pratt and Zape (2017) Model of Social and Psychosocial Disability Identity Development	Acceptance Status Relationship Status Adoption Status Engagement Status

Response to Disability

Until recently, the stages' theories of adaptation to disability (STADs) proposed that there are predictable or "normal" stages of responding to a disability (Bishop, 2005; Chan et al., 2009; Linveh & Parker, 2005). Linveh and Parker's (2005) research demonstrates that these STADs theories have traditionally been applied only to the individual who is experiencing the disability and ignores several additional, and very important, psychosocial factors. Taken from the Kubler-Ross (1965) Stages of Loss Theory, most existing STADs' models include six phases or stages that a person with a disability is likely to experience; they are: shock, defensive retreat, depression or mourning, personal questioning, and finally, integration (Kübler-Ross & Kessler, 2014; Smart, 2009).

More recent academic research, however, demonstrates that although most people with disabilities have these same generalized experiences that are analogous to the phases of the grieving process when dealing with an acquired disability, there are other significant considerations that the stages' models fail to address when the disability is congenital (Linveh & Wilson, 2003; Smart, 2009). Smart contends there is an important distinction concerning the individual responses to disability between those with acquired disabilities versus those with congenital disabilities. The first of these is in the case of congenital disabilities. With congenital disabilities, the parents, siblings, and often grandparents, progress through these stages, not necessarily the person with a disability (Smart, 2009). It is also important to note that the person with a congenital disability knows no other way of life other than the one she was born with (Smart, 2009). Therefore, it is a logical conclusion that the individual is more likely to progress through the "typical" stages of external environmental control development, very similar to a child born without a disability. It is also a logical conclusion to assert that a child born with a

congenital disability does not adapt to her environment, rather she develops the coping mechanisms that most typically developing children possess in order to manage her environment (Chan et al., 2009).

Adaptation versus Individual Response to Disability

According to Smart (2009), another primary weakness of the stages' models concerns the terminology of "adaptive" and "adjusting" when referring to an individual's response to disability. The differences between what Smart describes as the preferred term of "individual response" to disability versus the antiquated term of "adaptation" to disability should be explained. Smart (2009) gives four reasons why the term "response" is now the preferred term in the existing academic literature when describing a person's reaction to acquiring (or living with) a disability. These reasons include: the individual meaning ascribed to the disability is what is important and not the disability itself; there are different types of acceptance other than simply psychological; the word "response" is less pathologizing than "adaptation," "adjustment," or "acceptance," and the individual must cope with and respond to the disability throughout her/his life (Smart, 2009).

Finally, the last factor Smart (2009) recommends consideration of when assessing a people with disabilities' response to disability that the stages' models omit is the individual's environment. Factors like education level, economic security, family support, the availability of treatment and the stigma and prejudice that exist within the individual's community, all influence the disability experience (Bishop, 2005; Chronister et al., 2009; Livneh & Antonak, 2005; Smart 2009). For example, some major environmental factors to consider include: the degree of prejudice within the individual's community; discrimination toward type and severity of disability; and whether the individual is also subject to prejudice and discrimination because of

other perceived identities such as belonging to cultural/ethnic/racial minority groups. The literature supports the idea that the degree of stigma and prejudice the individual experiences will directly impact the individual’s response to the disability (Smart, 2009; Thomas & Smith., 2008).

Medical Model versus Social Model

These models represent an overarching perception of disability, both by mainstream society and by those with disabilities. The differences between the two orientations to disability are outlined in Table 5.

Table 5

Medical versus Social Model of Orientation to Disability

Medical Model Thinking	Social Model Thinking
Person is “faulty”	Person is valued
Diagnosis by medical professional	Strengths and needs defined by self and others
Labeling	Identify barriers and develop solutions
Impairment becomes focus of attention	Outcome based program designed
Segregation and alternative services	Training for PERSON WITH A DISABILITY, family, and disability professionals
Ordinary needs put on hold	Relationships nurtured
Reentry if “normal” enough or permanent exclusion	Diversity welcome, feelings of inclusion
Society remains unchanged	Society evolves

In the past, most orientations toward disability were based on a medical model and viewed disability as undesirable with a stigmatized status (e.g., Goffman, 1963). The medical model perspective had the ultimate goal for people with disabilities to achieve “normalization” or a lifestyle as close to possible to that of people without disabilities (Darling & Heckert, 2010). In recent years, a social model of disability has become more popular (Oliver, 1996). The social model suggests that, unlike people who are sick, individuals with disabilities do not need to adopt the norms of the non-disabled majority, nor do they need to “get well.” Conversely, it is society and its practices that need to accept and accommodate difference. According to Hahn and Belt (2004) and Linton (1998), adherence to a social model has been linked to activism. The belief that disability is a social problem, rather than a personal one, is compatible with activities intended to create social change (Darling & Heckert, 2010). This social justice movement has also been shown to positively impact people with disabilities’ attitudes and self-perceptions (Putnam, 2005).

Figure 2 shows the interconnectedness of the theoretical tenets previously discussed in the review of literature and how SIT (Tajfel, 1982) and SCT (Turner, 1982) specifically, assert that contextual and environmental influences, both positive and negative, can impact identity satisfaction in any minority group. In this graphic visualization of the social devaluation of minority groups, specifically people with disabilities, it is clear that a more positive sense of self and the more valued a person feels, the easier it is to combat socially constructed practices like stigmatization and exclusion. This figure also demonstrates the impact a positive identity has on overall life satisfaction.

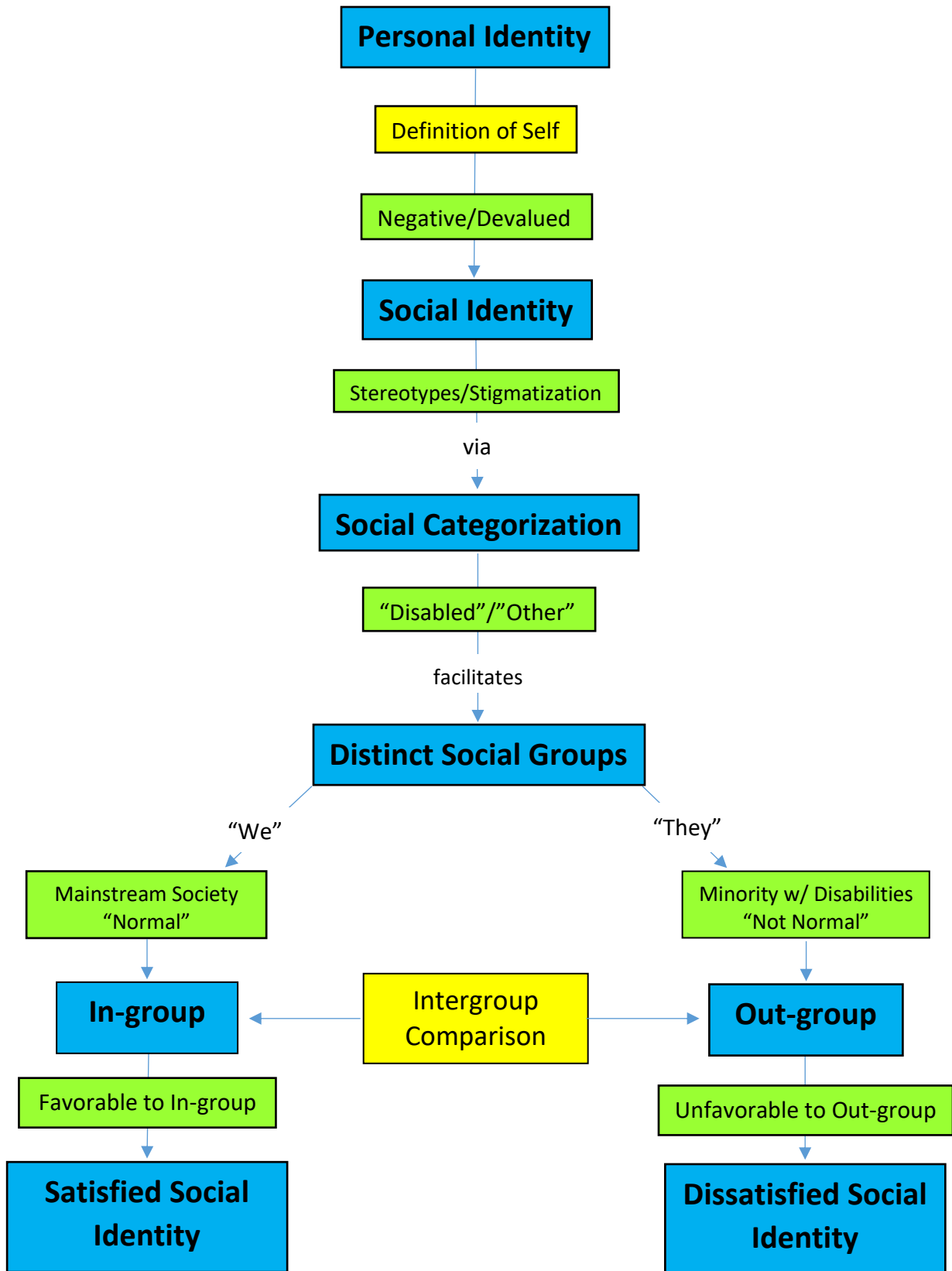


Figure 2. Social Identity Theory and Disability Identity

CHAPTER 3. METHOD OF STUDY AND INSTRUMENTATION

Introduction

Chapter I provided an introduction and theoretical framework for this study, statement of the research problem, purpose of the study, research questions, hypotheses, definition of terms, significance, limitations, and assumptions of the study. The purpose of this descriptive group design study was to partially replicate and extend the study by Darling and Heckert (2010) that investigated the impact age had on disability identity. Instead, this study investigated the impact that disability type (congenital or acquired) had on disability identity development. For this study, people with disabilities who utilize the State of Alabama Independent Living Centers and the Alabama Head Injury Foundation's peer support groups were recruited as participants. These individuals were all over the age of 19 and had a disability that was either congenital or acquired. Chapter II presented a literature review of identity development theory and disability identity development theory including studies and models related to both. Chapter III discusses the design of the study, sources of data, profiles of the five sites used in the study, data collection procedures, privacy and confidentiality of data collected, instrumentation, data collection procedures, and method of procedure.

Measuring Disability Identity

This study was a partial replication and extension of the Darling and Heckert (2010) study that focused on the association with disability orientation and aging. Orientation toward disability is related to, but broader than, the concept of disability identity (Darling & Heckert,

2010). In the Darling and Heckert (2010) study, orientation toward disability is conceptualized to include disability identity, which includes feelings of pride versus shame and feelings of exclusion/dissatisfaction versus feelings of inclusion/satisfaction; adherence to either a medical or social model of disability; and, level of disability rights activism. However, this study focused only on disability identity and the impact disability type (congenital or acquired) had on individual self-concept as evidenced by a) feelings of pride versus shame, b) feelings of inclusion and dissatisfaction versus feelings of inclusion and satisfaction, c) adherence to the medical model of disability, or d) adherence to the social model of disability. This study did not examine the impact congenital or acquired disabilities had on disability rights activism, nor did it attempt to predict orientation to disability. The Darling and Heckert study included a qualitative piece (n=10), as well as a quantitative piece (n=388) using the Questionnaire on Disability Identity and Opportunity (QDIO) survey instrument developed and validated by the authors (2010). Analysis of the quantitative data suggested that respondents had widely diverging orientations toward disability. After performing the factor analysis that yielded the aforementioned subscales (**dependent variables**), each item was cross-tabulated with the **independent variable** of age. Results suggested that older people were more likely to espouse a medical model (e.g., desiring a cure, believing “doctors know best”) to feel excluded from social participation (e.g., disability keeps them from their social life), and to reject an identity of Disability Pride (although they were more likely to think of themselves as “disabled” [sic], they did not view this identity in positive terms). In addition, the results showed that life satisfaction decreased with age. Age was negatively associated with length of time with disability. That is to say, young adults were more likely to have had their disability since birth (congenital) and to have had their disability for a longer period of time (Darling & Heckert, 2010).

In the Darling and Heckert study, mean subscale scores for the four factors – disability pride (four items), exclusion/dissatisfaction (four items), social model (seven items), and personal/medical model (eight items) – were calculated with high scores reflecting agreement with each of these factors. A multiple analysis of variance (MANOVA) was then performed on the four factors with age as the **independent variable**. The Darling and Heckert (2010) results revealed significant relationships ($p < 0.000$) between age and Factor 1 (disability pride) and between age and Factor 2 (exclusion). Younger respondents were more likely to agree with the items associated with disability pride as evidenced by higher average scores. Older respondents were more likely to agree with the items associated with exclusion, and to report perceiving higher average levels of exclusion/dissatisfaction. Age was a significant predictor of level of disability pride. Middle-aged respondents had a significantly lower level of disability pride than young adults, as did older respondents. With regard to exclusion, age was again a significant predictor. Middle-aged respondents reported significantly greater levels of feeling excluded than young adults. Older respondents also felt more excluded than young respondents, although the difference was not as great as it was for middle-aged respondents and was not statistically significant. Age was not a significant predictor of the social model subscale nor was it a significant predictor of the medical model subscale. Therefore, their results showed that older people appeared to be less likely to adopt newer views such as the social model and disability pride. Stigma and the medical model have been the normative views of disability for many years, and older individuals were likely to have been socialized to adhere to these views. As the Darling and Heckert (2010) results suggest, they also were less likely than younger people to use email or the Internet, often the primary means of disseminating the social model.

Design of the Study

This descriptive group design research study used a survey method to investigate the perceived impact disability type (congenital or acquired) had on disability identity development. It was a partial replication and extension of the Darling and Heckert (2010) study that investigated the impact that age had on disability identity development and orientation to disability. The **dependent variables** for this study were the four constructs used to measure disability identity on the Questionnaire of Disability Identity and Opportunity (QDIO) developed by Darling and Heckert (2010). Those constructs are a) disability pride versus shame, b) exclusion and dissatisfaction versus inclusion and satisfaction, c) affirmation of the personal/medical model of disability, and d) affirmation of the social model of disability. The **independent variable** was disability type consisting of two levels: congenital and acquired. Instead of using MANOVA, as in the Darling and Heckert study, ANOVA was used in this study because there was one independent variable (disability type) that consisted of two levels or groupings: congenital and acquired.

Sources of Data

Population. The population this study focused on was people with disabilities, both congenital and acquired, who were over the age of 19.

Sample. The convenience sample was individuals with congenital and acquired disabilities who utilize the Independent Living Centers in the State of Alabama and individuals with disabilities who utilize the Alabama Head Injury Foundation's (AHIF) peer support group services.

There are three Centers for Independent Living in the State of Alabama (ADRS, 2017). To be eligible for independent living services one must meet the following criteria:

- An individual must have a significant disability.
- The disability must limit the individual's ability to maintain independence.
- There must be evidence that the receipt of services will improve the individual's ability to retain independence.

These centers offer the following services:

- peer support from others with significant disabilities
- information and referral services to other resources that offer support and assistance to people with disabilities
- independent living skills training
- self-advocacy
- guidance and counseling services (ADRS, 2017)

In addition to people with disabilities who utilize the services of the Alabama Centers for Independent Living, people with traumatic brain injury (TBI) who participate in the Alabama Head Injury Foundation's (AHIF) regional peer support groups are also included in the sample. The mission of AHIF is to improve the quality of life for survivors of traumatic brain injury and their families. AHIF provides the information to help clients and families understand the results of traumatic brain injuries. AHIF also helps access available resources and provides services and programs which meet the unique needs of individuals with TBI as well as spinal cord injuries (SCI) in certain programs (AHIF, 2017). Eligibility for AHIF services require clients to either have a traumatic brain injury or a spinal cord injury that limits their ability to maintain independence (AHIF, 2017).

A non-probability cluster sample technique was used to select the convenience sample. The three independent living sites included one in the northern region of the state located in an

urban area (site A), one in the central region of the state located in an urban area (site B), and the third site is in the southern region of the state, also near an urban area (site C). The two AHIF support groups included one in the central region of the state located in an urban area (site D) and one in the southern region of the state located near a medium-sized city (site E) for a total of five data collection sites. Please see *Appendix B* for the data collection site map. All consumers who receive services at the Centers for Independent Living and from AHIF in these areas of the state were given an opportunity to respond to the survey.

Instrumentation. The instrument that was administered in this research study was the Questionnaire on Disability Identity and Opportunity (QDIO) developed by Darling and Heckert (2010). Darling and Heckert designed the QDIO to measure both the components of disability orientation (identity, model, and role) and access to opportunities for integration into mainstream society and into the disability subculture. The first part of the QDIO are 30 statements regarding attitudes, beliefs, and perceptions about disability. A 5-point Likert scale was used for responses ranging from *Strongly Agree* to *Strongly Disagree*. The instrument was validated using a national convenience sample of people with disabilities (N=388), and the exploratory factor analysis produced four constructs: a) Disability Pride; b) Exclusion and Dissatisfaction; c) Social Model; and d) Personal/Medical Model (Darling & Heckert, 2013). Reliability analysis revealed Cronbach's alpha levels that were respectable for three of the subscales: Disability Pride = 0.78; Exclusion/Dissatisfaction = 0.73; Social Model = 0.72, and marginally acceptable for the Personal/Medical Model subscale (alpha = 0.63). The alpha coefficients were deemed acceptable given the relatively small number of items in the subscale and the fact that the instrument is self-report (Darling & Heckert, 2010). The second part of the original QDIO contained 14 questions regarding participant demographics. With permission from the

instrument developers, the researcher added one demographics question about living arrangements, giving the survey administered in this study 15 demographics questions.

Documentation of permission to add the living arrangements question to the demographics section can be found in *Appendix D* of this document. The QDIO can be administered by an interviewer or self-administered in approximately 20 minutes (Darling & Heckert, 2010).

Privacy and Confidentiality of Data Collected

Proper steps were taken to ensure the privacy and confidentiality of the data collected. The researcher obtained permission from the Institutional Review Board (IRB) at Auburn University to conduct the study. A copy of the IRB approved Information Letter is included in *Appendix C*. Data were recorded and analyzed in an electronic platform, Statistical Package for the Social Sciences (SPSS). Only the researcher had access to the data, as the database is username and password protected. Data obtained in connection with this study were reported in the aggregate and remained anonymous with no identifiable information collected. Surveys were shredded after data entry and analysis were complete.

Data Collection Procedures

The QDIO survey instruments along with an Auburn University Institutional Review Board (IRB) stamped approved information letter that provided informed consent were distributed by the researcher at the three Independent Living Centers and the two AHIF support groups in five one-day, one-hour sessions. The researcher distributed the IRB stamped Information Letter and read it aloud to consent participants then passed out the survey instrument. Each question on the survey was also read aloud by the researcher to ensure all participants understood all questions. Individuals were able to complete the instrument in approximately 20 minutes. After each participant finished the survey, the instruments were

returned to a drop box provided by the researcher by each participant with no identifiable information. The researcher made the decision to go to the five sites to collect data in an effort to increase the likelihood of obtaining a higher response rate which will provide greater confidence in the results (Patten, 2014). Surveys were stored in the researcher's locked office, inside a locked cabinet in the Dawson Building on the Auburn University campus until data analysis was completed. All data were reported in aggregate form and all surveys were shredded after data entry and analysis was completed.

Method of Procedure

Descriptive data such as means and percentages were calculated to address the first research question regarding the demographics of the sample. A one-way between groups analysis of variance (ANOVA) was conducted to examine each null hypothesis. The first null hypothesis addressed the second research question regarding mean differences between congenital versus acquired (disability type) and reported feelings of pride versus shame. The second null hypothesis addressed the third research question regarding mean differences between congenital versus acquired (disability type) and reported feelings of exclusion and dissatisfaction. The third null hypothesis addressed the fourth research question regarding mean differences between congenital versus acquired (disability type) and affirmation of the medical model of disability. Finally, the fourth null hypothesis addressed the fifth research question regarding mean differences between congenital versus acquired (disability type) and affirmation of the social model of disability. Throughout the study, original data from the instrument were secured in a locked cabinet in the researcher's office. Again, no identifiable data were collected and therefore could not be traced back to any of the participants.

Summary

This chapter discussed the methodology used in this study. The sources of data, profiles of the data collection sites, privacy and confidentiality of data collected, instrumentation, data collection procedures, and method of procedure. The data analysis and results of the study are presented in Chapter 4.

CHAPTER 4. DATA ANALYSIS AND RESULTS

Chapter I provided an introduction and theoretical framework for this study, statement of the research problem, purpose of the study, research questions, hypotheses, definition of terms, significance, limitations and assumptions of the study. The purpose of this study was to investigate the impact that disability type had on disability identity development as evidenced by reported feelings of pride versus shame, reported feelings of exclusion and dissatisfaction versus inclusion and satisfaction, and adherence to either the medical or the social model of disability. Chapter II presented a review of the literature related to identity development theory and disability identity. Chapter III discussed the design of the study, sources of data, profiles of sites used in this study, data collection procedures, privacy and confidentiality of data collected, instrumentation, and method of procedure. Chapter IV focuses on the results of the data analysis.

Data Analysis

The **independent variable** in the study was *disability type* and the final analysis included two levels or grouping variables: *congenital* and *acquired*. Because the sample (N=47) was relatively small and the demographic question regarding length of time with disability had four answer choices: a) *since birth*, b) *less than 5 years*, c) *5–10 years*, and d) *more than 10 years*, the length of time with disability variable was collapsed and recoded in SPSS: a) *since birth* became *congenital* and choices b) through d) were collapsed and recoded into one variable, *acquired*. Therefore, rather than reporting the length of time with disability, the new independent variable

of *disability type* was created and divided into two groups: congenital and acquired. The **dependent variables** included the four subscales on the QDIO that measured the following constructs related to disability identity: a) disability pride versus shame, b) feelings of exclusion and dissatisfaction versus feelings of inclusion and satisfaction, c) affirmation of the medical model of disability, and d) affirmation of the social model of disability.

Descriptive data such as frequencies and percentages were summarized for the demographic questions regarding number of participants, gender, age, ethnicity, marital and employment status, geographic location and living arrangements (not included in the Darling and Heckert study), education level, assistance with activities of daily living, social activities, activism, and annual household income. This information was used to answer research question one. Each null hypothesis developed for research questions two through five was tested using a one-way between-groups ANOVA in an effort to determine if there were statistically significant mean differences between individuals with congenital disabilities versus acquired disabilities on reported feelings of disability pride, feelings of exclusion and dissatisfaction, affirmation of the medical model of disability, or affirmation of the social model of disability.

Results of Research Question One

The first research question was: What are the demographics of the sample? Participants identified demographic characteristics that can be found in Table 6 and include the following information: gender, ethnicity, age, marital status, employment status, annual household income, geographic location, living arrangements, educational level, assistance needed for activities of daily living, frequency of social activities, and participation in activist activities.

Table 6

Demographics of Participants

Characteristic	N (%)
Total Sample	47 (100%)
Disability Type	
Congenital	24 (51%)
Acquired	23 (49%)
Specific Disability	
Deaf or Hard of Hearing	22 (46.8%)
Mobility	15 (31.9%)
Cognitive	12 (25.5%)
Speech	12 (25.5%)
Vision	8 (17%)
Cosmetic	2 (4.3%)
Other	0 (0%)
Gender	
Male	29 (61.7%)
Female	18 (38.3%)
Age	
19–35	16 (34%)
36–64	26 (55.3%)
65+	5 (10.6%)
Ethnicity	
White	32 (68.1%)
African American	11 (23.4%)
Latino	2 (4.3%)
Native American	1 (2.1%)
Asian American/Pacific Islander	1 (2.1%)

(table continues)

Table 6 (continued)

Characteristic	N (%)
Marital Status	
Never married	20 (42.6%)
Married	17 (36.2%)
Separated/Divorced	8 (17%)
Widowed	2 (4.3%)
Employment Status	
Full-time	18 (38.3%)
Part-time	5 (10.6%)
Unemployed/Homemaker	12 (25.5%)
Retired	7 (14.9%)
Annual Household Income	
Under \$25,000	19 (40.4%)
25–50K	17 (36.2%)
50–100K	10 (21.3%)
Over 100K	1 (2.1%)
Education Level	
High School	13 (27.7%)
Some college	11 (23.4%)
College	9 (19.1%)
Some graduate school	1 (2.1%)
Graduate school	13 (27.7%)
Geographic Location	
Small town	11 (23.4%)
Rural	5 (10.6%)
Medium to large city	12 (25.5%)
Suburb	3 (6.4%)

(table continues)

Table 6 (continued)

Characteristic	N (%)
Living Arrangements	
Alone	11 (23.4%)
With spouse or partner	17 (36.2%)
Family or friends	15 (31.9%)
Full-time caregiver	2 (4.3%)
Part-time caregiver	2 (4.3%)
Assistance with Activities of Daily Living	
All	3 (6.4%)
Some	12 (25.5%)
None	32 (68.1%)
Frequency of Social Activities	
More than once a week	13 (27.7%)
Once or several times a month	28 (59.6%)
Less than once a month	5 (10.6%)
Specific Social Activities	
Talking on the phone	44 (93.6%)
E-mail	40 (85.1%)
Accessing disability-related websites	23 (48.9%)
Social media or on-line shopping	37 (78.7%)
Disability-related meetings/activities	35 (74.5%)
Religious services	27 (57.4%)
Magazines/newsletters from disability organizations	10 (21.3%)
Activism	
5 or more times	6 (12.8%)
Less than 5	15 (31.9%)
Once	3 (6.4%)
Never	23 (48.9%)

The 47 respondents in the sample population ranged in age from 19 to 65+. The largest number of respondents, 55.3% (n=26), were in the 36–64 age range. Of those 47 participants, 51% (n=24) reported congenital disabilities and 49% (n=23) reported acquired disabilities. Of note, out of the 24 participants reporting congenital disabilities, 22 of them had a sensory disability (i.e., Deaf or hard of hearing). See Table 6 for the breakdown of specific disabilities reported. There were 61.7% (n=29) male respondents and 38.3% (n=18) female respondents. The majority of respondents, 68.1% (n=32), were White and 23.4% (n=11) were African American. The ethnicity of the remaining 8.5% (n=4) is broken down in Table 6. For marital status, 42.6% (n=20) had never been married and 36.2% (n=17) were currently married. There were 48.9% (n=23) that reported either full-time or part-time employment, while 51% (n=24) reported being unemployed, retired, or were full-time students. Geographically, 34% (n=16) reported living in small towns or rural areas, while 31.9% (n=15) reported living in cities or suburbs. Only 8.6% (n=4) reported living with a full-time or part-time caregiver. The living arrangements of the remaining respondents were 23.4% (n=11) reported living alone, 36.2% (n=17) reported living with friends or family members, and 36.2% (n=17) reported living with a spouse or partner. All 47 respondents reported having completed high school while 19.1% (n=9) had a college degree, and 27.7% (n=13) held a graduate degree. Household income reported had 40.4% (n=19) making under \$25,000 per year, 36.2% (n=17) making \$25,000-\$50,000 per year, and the remaining 23.4% (n=11) making over \$50,000 per year. The majority of respondents, 68.1% (n=32), reported not needing any assistance with activities of daily living while 25.5% (n=12) reported needing some assistance. The majority of respondents, 59.6% (n=28), also reported participating in social activities one to several times a month with 27.7% (n=13) reporting participation in social activities more than once a week. For specific types of social

activities, please refer to Table 6. Many participants, 48.9% (n=23), had never participated in disability rights activities while 31.9% (n=15) reported participating in disability rights activities less than five times. See Table 6 for a complete breakdown of all participant demographics reported.

Results of Research Question Two

The second research question was: Are there significant mean differences in reported feelings of disability pride for individuals with acquired disabilities versus individuals with congenital disabilities? The following null hypothesis was formulated to answer the second research question:

Ho₁: There are no significant mean differences between individuals with congenital disabilities versus those with acquired disabilities on reported feelings of disability pride.

A one-way between-groups ANOVA was conducted to explore the impact disability type had on feelings of disability pride, as measured by the QDIO. Higher mean scores reflected agreement with the construct. Participants were divided into two groups according to the independent variable. Group one (n=24) included respondents with congenital disabilities and Group two (n=23) included respondents with acquired disabilities. There was a statistically significant difference at the $p < .05$ level in the means of the two groups: $F(1,45) = 7.712, p = .008$. The effect size for question two, calculated using eta squared, was large for ANOVA at .15 (Salkind, 2011). The power for question two with a sample size of $n = 47$ was acceptable at .776 (Salkind, 2011). Therefore, the null hypothesis for research question two that there was no difference in the means between those with congenital disabilities versus those with acquired disabilities on reported feelings of disability pride was rejected. Table 7 shows these data.

Table 7

Results of Research Question Two – Disability Pride

Disability Type	Range	M	SD	Sig.
Congenital	7.0 – 20.0	14.7	4.2	.008
Acquired	5.0 – 18.0	11.6	3.4	

Results of Research Question Three

The third research question was: Are there significant mean differences in reported feelings of exclusion for individuals with congenital disabilities versus individuals with acquired disabilities? The following null hypothesis was formulated to answer the third research question:

Ho₂: There are no significant mean differences between individuals with congenital disabilities versus those with acquired disabilities on reported feelings of exclusion.

A one-way between-groups ANOVA was conducted to explore the impact disability type had on feelings of exclusion and dissatisfaction, as measured by the QDIO. Higher mean scores reflected agreement with the construct. Again, participants were divided into two groups according to the independent variable. Group one (n = 24) were those with congenital disabilities and Group two (n = 23) were those with acquired disabilities. There was a statistically significant difference at the $p < .05$ level in the means of the two groups: $F(1,45) = 9.100, p = .004$. The effect size for question three was also large for ANOVA at .17 (Salkind, 2011). Statistical power for question three was .839, which is above the minimum acceptable level of .80 (Salkind, 2011). Therefore, the null hypothesis that there are no significant mean differences between congenital versus acquired on reported feelings of exclusion and dissatisfaction was rejected. Table 8 show these data.

Table 8

Results of Research Question Three – Exclusion and Dissatisfaction

Disability Type	Range	M	SD	Sig.
Congenital	7.0 – 19.0	10.8	3.0	.004
Acquired	8.0 – 17.0	13.1	2.4	

Results of Research Question Four

The fourth research question was: Are there significant mean differences in affirmation of the medical model of disability for individuals with congenital disabilities versus those with acquired disabilities? The following null hypothesis was formulated to answer the fourth research question:

Ho₃: There are no significant mean differences between individuals with congenital disabilities versus those with acquired disabilities and affirmation of the medical model of disability.

A one-way between groups ANOVA was conducted to explore the impact disability type had on affirmation of the medical model of disability. Higher mean scores reflected agreement with the construct. There was a statistically significant difference at the $p < .05$ level in the means of the two groups: $F(1,45) = 18.107, p = .000$. The effect size for question four, calculated using eta squared, was large for ANOVA at .29 (Salkind, 2011). The power for research question four was more robust than all other research questions at .986 (Salkind, 2011). Therefore, the null hypothesis that there are no significant mean differences between congenital

versus acquired on affirmation of the medical model was rejected. These results are shown in Table 9.

Table 9

Results of Research Question Four – Affirmation of the Medical Model

Disability Type	Range	M	SD	Sig.
Congenital	12.0 – 34.0	21.2	6.4	.000
Acquired	18.0 – 38.0	28.0	4.4	

Results of Research Question Five

The fifth research question was: Are there significant mean differences in affirmation of the social model of disability for individuals with congenital disabilities versus those with acquired disabilities? The following null hypothesis was formulated to answer the fourth research question:

Ho₄: There are no significant mean differences between individuals with congenital disabilities versus those with acquired disabilities and affirmation of the social model of disability.

A one-way between groups ANOVA was conducted to explore the impact disability type had on affirmation of the social model of disability. Higher mean scores reflected agreement with the construct. Participants were again divided into two groups according to the independent variable. Group one (n = 24) were respondents with congenital disabilities and Group two (n = 23) were respondents with acquired disabilities. There was a statistically significant difference at the $p < .05$ level in the means of the two groups: $F(1,45) = 5.585, p = .022$. The effect size for

question five using eta squared was .11 which is still moderate to large for ANOVA (Salkind, 2011). The power for research question five was respectable at .638 (Salkind, 2011). Therefore, the null hypotheses that there were no significant mean differences between congenital versus acquired and affirmation of the social model of disability was rejected. This information is depicted in Table 10.

Table 10

Results of Research Question Five – Affirmation of the Social Model

Disability Type	Range	M	SD	Sig.
Congenital	23.0 – 35.0	30.1	4.0	.022
Acquired	20.0 – 35.0	27.3	4.0	

Summary

This chapter discussed the results of the data analysis. Descriptive data presented in this chapter summarized the demographic characteristics (see Table 6) of the sample and answered question one: What are the demographic characteristics of the sample? The chapter also provided the results for the one-way between groups’ ANOVAS used to answer research questions two through five. Results of the first ANOVA for research question two for mean differences between congenital versus acquired on reported feelings of disability pride were statistically significant at the $p < .05$: $F(1,45) = 7.712, p = .008$ (see Table 7). Therefore, the null hypothesis that there were no statistically significant differences between the means of congenital versus acquired on reported feelings of disability pride was rejected.

Results of the second ANOVA for research question three for the mean differences between congenital versus acquired on reported feelings of exclusion were statistically significant at the $p < .05$: $F(1,45) = 9.100$, $p = .004$ (see Table 8). Therefore, the null hypothesis that there were no statistically significant mean differences between congenital versus acquired on reported feelings of exclusion was rejected. Results of the third ANOVA for research question four for the mean differences between congenital versus acquired on affirmation of the medical model of disability were statistically significant at the $p < .05$: $F(1,45) = 18.107$, $p = .000$ (see Table 9). Therefore, the null hypothesis that there were no statistically significant mean differences between congenital versus acquired and affirmation of the medical model was rejected. Results of the fourth ANOVA for research question five for the mean differences between congenital versus acquired on affirmation of the social model of disability were statistically significant at $p < .05$ level in the means of the two groups: $F(1,45) = 5.585$, $p = .022$ (see Table 10). Therefore, the null hypothesis that there were no statistically significant mean differences between congenital versus acquired and affirmation of the social model was also rejected. An overview of this study, summary of results, limitations, implications, conclusion, recommendations for practical applications, and summary are presented in Chapter 5.

CHAPTER 5. SUMMARY AND CONCLUSIONS

Chapter I provided an introduction and theoretical framework for this study, statement of the research problem, purpose of the study, research questions, hypotheses, definition of terms, significance, limitations and assumptions of the study. The purpose of this study was to investigate the impact that disability type had on disability identity development as evidenced by reported feelings of pride versus shame, reported feelings of exclusion and dissatisfaction versus inclusion and satisfaction, and affirmation of either the medical or the social model of disability. For this study, individuals with disabilities, both congenital and acquired, who received services through one of the State of Alabama Independent Living Centers or The Alabama Head Injury Foundation, were selected as participants. Chapter II presented a review of literature relevant to the evolution of identity theory and disability identity. It also presented an overview of the particularly relevant identity theories to this study that included Social Role Valorization (SRV), Social Identity Theory (SIT), Self-Categorization Theory (SCT), Feminist Theory, and Post-Modernist perspectives. Chapter III discussed the design of the study, sources of data, profiles of sites, data collection procedures, privacy and confidentiality of data collected, instrumentation, and method of procedure. Chapter IV focused on the results of the data analysis. This chapter will present an overview of the study, summary of results, limitations, implications, conclusion, recommendations, and overall summary.

Overview of the Study

Before one can begin to understand the concept of disability identity, an extensive literature review of the evolution of identity theory was conducted. Identity theory and models date back to, among others, Erickson's Psychosocial Stages of Identity Development (1965) and Marcia's Identity Status Model (1966). Individual, group, and intersecting identity development theories and models were included in the review of literature in an effort to better explain the more recent concept of disability identity development. Several traditional identity theories emerged that helped clarify the concept of social roles and social identities as they relate to minority group identity development, specifically disability identity development. Social Role Valorization (SRV) (Wolfensberger, 1972); Social Identity Theory (Tajfel, 1972); and Self-Categorization Theory (Turner, 1982) are all precursors to Postmodern conceptualizations of feminist theory regarding intersecting identities and how the social construction of labels and categories are not a function of the individual but rather a societal practice using power differentials and aimed at exclusion.

This research study partially replicated and extended the study by Darling and Heckert (2010) regarding the impact age had on disability identity but, instead, focused on the impact disability type (i.e. congenital versus acquired) had on disability identity development as measured by the factors on the Questionnaire on Disability Identity and Opportunity (QDIO) (Darling & Heckert, 2010). The researcher used a convenience sample by selecting five support group sites throughout Alabama that served people with disabilities. These sites served people with disabilities through the Alabama Department of Vocational Rehabilitation Services Independent Living Centers support groups or through the Alabama Head Injury Foundation support groups. Site and group supervisors were contacted to provide information about the

study, participation requirements of the study, and to request permission to administer the QDIO during one of the monthly support group meetings. In fall 2017, 47 people with disabilities completed the surveys that were administered at each of the five sites by the researcher.

Summary of Results

This study revealed the answers to the following research questions:

1. What are the demographic variables of this sample?
2. Are there significant mean differences in reported feelings of disability pride for individuals with acquired disabilities versus individuals with congenital disabilities?
3. Are there significant mean differences in reported feelings of exclusion and dissatisfaction for individuals with acquired disabilities versus individuals with congenital disabilities?
4. Are there significant mean differences in affirmation of the medical model of disability for individuals with acquired disabilities versus individuals with congenital disabilities?
5. Are there significant mean differences in affirmation of the social model of disability for individuals with acquired disabilities versus individuals with congenital disabilities?

The results for all five questions are summarized in detail in Chapter 4. Overall results suggest that individuals with congenital disabilities were more likely to have a better developed and more positive sense of disability identity than those with acquired disabilities. Individuals with acquired disabilities appeared less likely to adopt newer views such as the social model and disability pride into their overall sense of self. Historically, stigma and the medical model have been the normative views of disability, especially by those without disabilities. Individuals with

acquired disabilities seemed more likely to have adhered to these engrained societal norms before disability identity synthesis. This study provides information that may be useful to rehabilitation professionals regarding adaptation and response to disability between those with congenital disabilities versus those with acquired disabilities. In addition, the results have the potential to inform and expand the recent, yet growing body of knowledge regarding the variables that may impact positive disability identity development not found in the academic literature. Finally, the results support the previous academic research focused on disability identity development (e.g. Bogart, 2014, 2015; Darling & Heckert, 2010; Hahn & Belt, 2004; Kindermans et al., 2010; Zhang & Haller, 2013), as well as inform existing models of disability identity development (e.g. Darling & Heckert, 2010; Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017; Gibson, 2006; Gill, 1997; Hahn & Belt, 2004; Putnam, 2005).

Conclusions

To the extent that the data collected in this study were valid and reliable and the assumptions of the study were appropriate and correct, the researcher made the following conclusions based on the results of this study:

1. There was a statistically significant difference in the means between those with congenital disabilities versus those with acquired disabilities on feelings of disability pride.

Those individuals with congenital disabilities had higher mean scores on feelings of disability pride than did those with acquired disabilities. This supports the literature that the idea of disability pride has been associated with a shift in society from a medical model that views disability as a pathological condition to a social model that views disability as a normal form of human diversity (Oliver, 1996; Swain & Cameron, 1999). Various writers have noted parallels

between positive constructions like disability pride and similar constructions, such as gay pride and black pride, among other minority groups (Darling, 2013).

2. There were statistically significant mean differences between individuals with congenital disabilities versus those with acquired disabilities on feelings of exclusion.

The mean was higher for feelings of exclusion among those with acquired disabilities than those with congenital disabilities. This also supports the existing academic literature that those born with congenital disabilities have had longer to adapt and have already achieved identity synthesis as opposed to currently being in turmoil over one's identity, as is often the case with those who have acquired a disability (Charmaz, 1995).

3. There were statistically significant mean differences between individuals with congenital disabilities versus those with acquired disabilities and affirmation of the medical model of disability.

Those with congenital disabilities had lower mean scores on affirmation of the medical model of disability than did those with acquired disabilities. This finding supports the literature in that those with acquired disabilities may still be searching for a "cure" or a way to minimize the effects of the disability. They often view the disability as a stigmatizing aspect of identity and have feelings of mourning and loss for the pre-disability identity (Smart, 2009).

4. There were statistically significant mean differences between individuals with congenital disabilities versus those with acquired disabilities and affirmation of the social model of disability.

Those with congenital disabilities had higher mean scores on the affirmation of the social model of disability than did those with acquired disabilities. Those who subscribe to a social model see a need for social change in the form of physical changes to the environment, such as

curb cuts and ramps, as well as changes in attitudes away from stigma and toward acceptance (Darling, 2010).

Implications

The results of this study suggest several implications:

1. While people with disabilities are often referred to collectively as a minority group, differences in disability identity development do exist between those with congenital disabilities versus those with acquired disabilities.

Even though “people with disabilities” is often used to refer to a collective minority group, disability is a highly individualized experience (Smart, 2009). Smart contends there is an important distinction concerning the individual responses to disability between those with acquired disabilities versus those with congenital disabilities. The first of these is in the case of congenital disabilities. With congenital disabilities, the parents, siblings, and often grandparents, progress through these stages, not necessarily the person with the disability (Smart, 2009). It is also important to note that the person with a congenital disability knows no other way of life other than the one she was born with (Smart, 2009). Therefore, it is a logical conclusion that the individual is more likely to progress through the “typical” stages of external environmental control development, very similar to a child born without a disability. It is also a logical conclusion to assert that a child born with a congenital disability does not adapt to her environment, rather she develops the coping mechanisms that most typically developing children possess in order to manage her environment (Chan et al., 2009).

2. Contact with others in the disability community, especially by those with an acquired disability, may improve and even speed up the process of positive disability identity synthesis.

Inspired by the civil rights struggle of other minority groups such as African Americans and women, people with disabilities have begun to define who they are and where their place is in society. They are beginning to demand a level of cultural competence, both from the greater society and from rehabilitation and medical professionals as well (Dunn & Andrews, 2015). According to Gill (1997), inaccessible environments, transportation systems, poverty, and stigma are barriers to community organizing and resources for those with disabilities. Categorization rooted in the Medical Model of Disability and antiquated social service delivery perpetuates separation and makes group unity difficult (Smart, 2009). Social values that see disability as a fate worse than death discourage individuals with disabilities from seeking out stigmatized peers. This drive for wholeness and definition has resulted in organizations and public policies that safeguard people with disabilities' rights as citizens as well as cultural efforts to celebrate differentness as valuable and a source of group strength and disability identity pride (Gill, 1997). This journey described by Gill (1997) portrays a growth process that involves at least temporary relinquishment of former attachments (or commitments), redefinition of self, and reconfiguration of relationships to others and society. All of the above-mentioned potential risks and rewards of the process mentioned earlier in this paper that Mahler (1968) refers to as separation-individuation, is the effort by people with disabilities to improve the prospects of integration and acceptance as a foundation for group identity development.

3. The results of this study and other studies like it that explore outside variables such as age and disability type (i.e., congenital versus acquired) have the potential to inform disability identity development models, rehabilitation, and even medical practices.

Models for disability identity development do exist but are few and relatively new to the academic literature. Some of these models represent a stage theory that implies individuals'

progress from one stage to the next. Others describe the phases or statuses, but do not imply a direct progressive relationship that one specific phase must be passed through before transitioning to the next one. Also of note, not all of these models are based on the same disability identity theoretical tenets. Some of these models were developed with the stages of grief in mind, others were interactional in nature. The results of this study support models such as the postmodern perspectives of interactional models of intersecting identity development as depicted in Figure 2 of this paper (Abes, Jones & McEwen, 2007).

Recommendations

Research in this area has important practical applications. In addition to increasing scholarly knowledge about the population of people with disabilities in general, the results of the QDIO could be used by practitioners to learn more about the identity formation of individuals with disabilities and the impact disability type may have on perceptions of identity, as well as contribute information that could be used to develop a more accurate model of disability identity development (Lyew, Mueller & Samples, 2017). In addition to a better understanding of how disability is incorporated into the overall sense of self, it is also possible that this research will provide a more in-depth and accurate picture of disability identity and orientation and the external influences that may have a significant impact. Therefore, a better understanding of disability identity development may result in interventions to promote those orientations to disability that are associated with better quality of life outcomes such as meaningful employment and social inclusion. Finally, policy makers need to be aware of the diversity of orientations toward disability when developing legislation or programs for this population. Social policy can increase or decrease opportunities for social inclusion for individuals with disabilities (Putnam, 2005).

Possible future research in the area of disability identity should include more mixed methods' approaches that contain a quantitative element as well as qualitative focus groups that give examples and stories of the lived experiences of the identity formation of those with disabilities. In addition to adding focus groups for a more in-depth picture of disability identity formation, future research in this area should also examine other demographic variables such as education level, socioeconomic status, gender, etc., and descriptive variables such as living arrangements, disability rights activism participation, and specific disability types for more insight into external variables that may influence disability identity.

Limitations

There were several limitations of note in conducting this study. The first of these is of the 24 respondents with congenital disabilities, 22 or 47% of them had sensory disabilities. Also, of the 47 respondents, an overwhelming majority, 32 or 68% were white. Finally, of the 47 respondents, 32 or 68% reported needing no assistance with activities of daily living.

Summary

“An essential core-concept of human dignity is that a person is not an object, not a thing” (Wright, 1987, p. 12).

This research study partially replicated and extended the Darling and Heckert (2010) study regarding the impact age had on disability identity but instead focused specifically on the impact disability type (congenital or acquired) had on disability identity development which included disability pride, feelings of exclusion and dissatisfaction, and affirmation of either the medical or social model of disability. The relationship between disability identity and disability acquisition has been thus far unexplored in the empirical literature. Disability identity and age/age of onset has been considered by Darling and Heckert (2010) and Hahn and Belt (2004),

but additional studies that focus on other variables like congenital versus acquired disabilities and how they impact disability identity are needed to a) demonstrate the power of choice and self-determination, b) to inform policy regarding disability rights, c) to inform rehabilitation practitioners about the differences in adaptation of the two groups, and d) to combat stigma and devaluation by self and others. Therefore, the focus of this study was the lack of information in the academic literature regarding the influence that disability type may have on disability identity development.

Forty-seven individuals with disabilities were recruited for this study from the Alabama Department of Rehabilitation Independent Living Services Division support groups and the Alabama Head Injury Foundation's support groups. Twenty-four individuals had congenital disabilities and 23 had acquired disabilities. Overall results from the Questionnaire on Disability Identity and Opportunity suggested that individuals with congenital disabilities were more likely to have a better developed and more positive sense of disability identity than those with acquired disabilities. Individuals with acquired disabilities appeared less likely to adopt newer views such as the social model and disability pride into their overall sense of self. Historically, stigma and the medical model have been the normative views of disability, especially by those without disabilities. Individuals with acquired disabilities seemed more likely to have adhered to these engrained societal norms before disability became part of their identity. This study provides information that may be useful to rehabilitation professionals regarding adaptation and response to disability between those with congenital disabilities versus those with acquired disabilities. In addition, the results have the potential to inform and expand the recent, yet growing body of knowledge regarding the external variables that may impact positive disability identity development that lead to better quality of life outcomes for individuals with disabilities.

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APPENDIX A

Questionnaire on Disability Identity and Opportunity

Questionnaire on Disability Identity and Opportunity

1. I don't think of myself as a disabled person.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

2. I would rather spend time with people with disabilities than with people without disabilities.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

3. I am a better person because of my disability.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

4. If I had a choice, I would choose not to have a disability.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

5. I am proud of my disability.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

6. My disability is an important part of who I am.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

7. I feel sorry for people with disabilities.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

8. Most of my friends have disabilities.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

9. Poor access and prejudice by employers are the main reasons why people with disabilities are unemployed.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

10. It isn't easy for people with disabilities to be treated as "normal."

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

11. People with disabilities need to fight for their rights more than nondisabled people do.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

12. The reason most people with disabilities are unemployed is that they are not able to do the jobs that are available.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

13. My disability limits my social life.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

14. My disability keeps me from working.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

15. The biggest problem faced by people with disabilities is the attitudes of other people.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

16. All buildings should be available to people with disabilities.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

17. I have a lot in common with other people with disabilities.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

18. I wish that someone would find a cure for my disability.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

19. Doctors and other medical professionals know what is best for people with disabilities.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

20. People with disabilities need to learn to change to living in a world in which most people are not disabled.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

21. I try to hide my disability whenever I can.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

22. I am familiar with the Americans with Disabilities Act and think it is a good law.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

23. I am familiar with the Disability Rights Movement and support its goals.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

24. People should try to overcome their disabilities.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

25. My disability improves my life.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

26. People with disabilities can never fit into “normal” society.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

27. In general, I am satisfied with the quality of my life.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

28. I am often left out of activities because of my disability.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

29. The people I care about always include me in activities I am able to enjoy.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

30. The most important thing for people with disabilities is to learn to accept what they cannot change.

- Strongly Agree
- Agree
- Not sure
- Disagree
- Strongly Disagree

Demographic Questions

Instructions: Please place a check in the box next to the choice that best describes you.

1. What is your gender?

- Male
- Female

2. What is your age?

- 19-35
- 36-64
- Over 65

3. What is your marital status?

- Never married
- Married
- Separated or divorced
- Widowed

4. What is your employment status?

- Work full-time
- Work part-time
- Unemployed or homemaker
- Retired
- Student

5. Where do you live?

- Small town
- Rural area
- Large city
- Medium-sized or small city
- Suburb of a large or medium-sized city

6. What are your living arrangements?

- Live alone with no caregiver
- Live with spouse/partner
- Live with family or friends
- Live with full-time caregiver
- Live with part-time caregiver
- Live in residential facility

7. What is the highest level of school you completed?

- Less than high school
- High school
- Some college
- College
- Some graduate school
- Graduate school

8. What is the nature of your disability or impairment? (If you have more than one, please check all that apply).

- Mobility (Difficulty in movement)
- Vision
- Hearing
- Speech
- Cognitive (Difficulty in thinking)
- Cosmetic (Difference in appearance or size)
- Other: Please specify: _____

9. How long have you had your disability or impairment (If you have more than one, please check the time that describes the condition you have had the *longest*).

- Since birth
- Less than 5 years
- 5 – 10 years
- More than 10 years

10. How much assistance do you need with activities of daily living (like bathing, dressing, shopping and cooking)?

- I need assistance with all activities
- I need assistance with some activities
- I don't need any assistance

11. About how often do you engage in social activities outside of your home, like visiting friends or eating out in restaurants?

- More than once a week
- Once or several times a month
- Occasionally, less than once a month
- Rarely or never

12. Have you ever participated in a demonstration, written a letter to your congressional representative, or engaged in another activity to try to increase the opportunities available to people with disabilities?

- Yes, many times
- Yes, a few times
- Yes, once
- No, never

13. Please check the activities in which you participate at least once a month:

- Talking on the telephone with family, friends, or acquaintances
- Using a computer to communicate by e-mail
- Using a computer to access disability-related websites on the internet
- Using a computer to access other websites like social media or shopping
- Going to meetings or activities sponsored by disability-related organizations
- Attending religious services
- Reading magazines or newsletters from disability-related organizations

14. Please check the category that best describes your total, annual household income:

- Under \$25,000
- \$25,000 - \$50,000
- \$50,000 - \$100,000
- Over \$100,000

15. Please check the category or categories that best describe your racial/ethnic background:

- European American (white)
- African American
- Latino or Hispanic
- Native American
- Asian American
- Other: _____

APPENDIX B

Data Collection Site Map



APPENDIX C

Institutional Review Board (IRB) Approved Stamped Information Letter



COLLEGE OF EDUCATION

DEPARTMENT OF

SPECIAL EDUCATION, REHABILITATION, AND COUNSELING

The Auburn University Institutional
Review Board has approved this
Document for use from
09/19/2017 to 09/18/2018
Protocol # 17-356 EP 1709

(NOTE: DO NOT AGREE TO PARTICIPATE UNLESS AN IRB APPROVAL STAMP WITH CURRENT DATES HAS BEEN APPLIED TO THIS DOCUMENT.)

INFORMATION LETTER

for a Research Study entitled

“Disability Identity: Disability Acquisition for Individuals with Disabilities”

You are invited to participate in a research study regarding disability identity in individuals with acquired and congenital disabilities. The study is being conducted by Angie Hall from Auburn University’s Department of Special Education, Rehabilitation, and Counseling. You were chosen as a participant because you have a disability that is either acquired or congenital and are age 19 or older.

What will be involved if you participate? If you decide to complete the survey, the instrument will be distributed and you will be asked to complete it and then drop it off in a drop box. Your total time commitment to complete the survey will be approximately 20 minutes.

Are there any risks of discomforts? The risks associated with participating in this study include possibly experiencing some discomfort sharing your perceptions and attitudes regarding your disability. To protect your identity, the researchers will not collect any personal identifying information and data analysis will be conducted anonymously.

Are there any benefits to yourself or others? There are no anticipated direct benefits to participating in the research study.

Will you receive compensation for participating? No.

Are there any costs? If you decide to participate, you will not incur any monetary costs.

If you change your mind about participating, you can withdraw from the study at any time. Your participation is completely voluntary. If you choose to withdraw, please stop answering the survey and remove yourself from the session. Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Auburn University, the Department of Special Education, Rehabilitation and Counseling, or the Alabama Head Injury Foundation.

Your privacy will be protected. Any information/data obtained in connection with this study will remain anonymous. We will protect your privacy and keep the data confidential. Data collected will be kept in the locked office of the primary researcher. Results of this study will be used to complete dissertation and may be published in a professional journal and/or presented at a professional conference.

If you have questions about this study, please ask them now or contact Angie Hall at 334.304.5559, ahm0016@auburn.edu or my major professor, Rebecca S. Curtis, PhD, at curtirs@auburn.edu or 334.844.7676. A copy of this document will be given to you to keep.

If you have questions about your rights as a research participant, you may contact the Auburn University Office of Research Compliance or the Institutional Review Board by phone at 334.844.5966 or via email at IRBadmin@auburn.edu or IRBChair@auburn.edu.

HAVING READ THE INFORMATION PROVIDED, YOU MUST DECIDE IF YOU WANT TO PARTICIPATE IN THIS RESEARCH PROJECT. IF YOU DECIDE TO PARTICIPATE, THE DATA YOU PROVIDE WILL SERVE AS YOUR AGREEMENT TO DO SO. THIS LETTER IS YOURS TO KEEP.

Investigator's signature Date

Printed name

Co-investigator Date

Printed name

<p>The Auburn University Institutional Review Board has approved this Document for use from <u>09/19/2017</u> to <u>09/18/2018</u> Protocol # <u>17-356 EP 1709</u></p>

APPENDIX D

Email Granting Permission to Use the QDIO

From: Rosalyn Darling
To: [Angie Hall](#)
Cc: aheckert@iup.edu
Subject: Re: Permission to use QDIO Instrument for Dissertation Research
Date: Friday, February 24, 2017 1:30:26 PM

Angie,

You are welcome to use the instrument as long as you credit the source in any written report/publication. Please note that the factor analysis for our sample might differ from yours (as has been true in some other research involving the instrument), so you probably should repeat that.

I also would be interested in hearing more about your research and your results.

Thanks for your interest in my work!

Roz

Rosalyn Benjamin Darling, Ph.D.
Professor Emerita, Indiana University of Pennsylvania and
Visiting Scholar, University of North Carolina-Chapel Hill

On Fri, 24 Feb 2017 17:15:33 +0000

Angie Hall <ahm0016@tigermail.auburn.edu> wrote:

> Dr. Darling,

>

> This email is an official request for permission to use the Questionnaire on Identity and Opportunity (QDIO) found in your book *Disability and Identity: Negotiating Self in a Changing Society*.

>

> I am also requesting to add one demographic question that asks about independent living status.

>

> My working title is *Disability Identity and Independent Living Status for Individuals with Disabilities*. I am proposing to examine how independently someone with a disability lives and the relationship that may have with identity, role, and model.

>

> Thank you in advance for your time and attention to this matter and I will be glad to provide you with more information if you need me to.

>

> I look forward to your response regarding using your instrument.

>

> Sincerest thanks,

>

> Angie Hall

> Graduate Research Assistant

> Auburn University Special Education, Rehabilitation and Counseling

> Center for Disability Research and Policy Studies

> Rm # 127