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**DON'T JUDGE A BOOK BY ITS COVER:**  
**CONTEXTUAL ANTECEDENTS OF IDENTITY COMPLEXITY IN**  
**INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES**

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Doctor of Philosophy  
Graduate Program in Social Work  
Written under the direction of Judith McCoyd, Ph.D.

And approved by

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## **ABSTRACT OF THE DISSERTATION**

Don't Judge A Book By Its Cover:

### **CONTEXTUAL ANTECEDENTS OF IDENTITY COMPLEXITY IN INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES**

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Dissertation Director:

Judith McCoyd, Ph.D.

This project explores the various processes Individuals with Developmental Disabilities (IWDD) engage in to make meaning of their lives. Exposure to and involvement in varied and enriched social environments is presumed to affect identity complexity and ultimately individuals' self-concepts. Findings indicate three overarching processes at work; Recognition (cognitive level), Response (emotional level) and Reconciliation (behavioral level) all of which act at varying levels of distance from the self (intrapersonal, extra-personal: known others, extra-personal: unknown others). These processes are reflexive and yield a foundational rationale for STOIC (the Social Theory Of Identity Complexity), the grounded theory derived from this research. Participants adopt various strategies to achieve a sense of well-being. Some seek to elevate their social status by a process I term 'hierarchy' i.e. assuming higher perceived valued identities such as a mentor, educator, advocate or artist (which enhances their identity complexity and ultimately self-concepts). Most of the participants work to

reinforce relationships with familiar others such as family and friends. Some also elevate their disability identity to a higher social category through networking with others with disabilities, advocating for rights and wearing their ‘disability identity’ with pride as indicated in their disability advocacy work or as exhibited in their artwork, writings and other artistic representations. By enacting these various strategies (Reconciliation), many participants exhibit resiliency and subsequently achieve a sense of well-being (Response) which feeds back on how they think about themselves (Recognition).

## **Acknowledgments**

‘Don’t judge a book by its cover’ is the title of a painting by a participant in this project and succinctly articulates the message that most of the participants in this study strived to express. I would like to believe this dissertation can be a vessel to bring this message to light and to honor and value those people who were so willing to share their pain, triumphs, despair and joy with me during the course of this project. I know I have become a better person for being in the presence of such tenacity of spirit and feel honored that they have agreed to share their stories with me. In addition to these courageous individuals, I would also like to acknowledge the caregivers, instructors, social workers and parents/guardians who granted me access via guardian consent, assisted me in learning how to understand the various communication styles, and worked with me to decipher complex communication boards and technology. These people gave of their time and expertise merely knowing that this project afforded the participants an opportunity to be heard and ‘seen.’

Next, I must extend my heartfelt thanks to my chairperson, Dr. Judith McCoyd who also displayed tremendous tenacity of spirit in reading through the many iterations of this final product. While always delivering a serious reckoning, her critiques and edits displayed humor, warmth and nurturance helping to propel me to create a work that I am truly proud of and honors the efforts of my participants. She welcomed my invitation to be my chair at a time when I was sincerely adrift with regards to how to best explore understanding life quality in IWDD from their point of view. Although she is not a disability scholar, she really ‘got’ what I was trying to do and helped me to realize my

vision. Words sincerely cannot express what it means to have her as a mentor, teacher, colleague and friend.

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‘Being with family and friends’ is an important theme emerging from my data and it is an important theme throughout my life. I need to end this with an acknowledgement of my family, my husband Marc and daughters: Abby and Sandi, who have stood by me

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Finally, I must also acknowledge those who are no longer here with me to follow my story to this point in time. My late dad, Arthur Fader was absolutely crushed when I left my first doctoral program 33 years ago (in biopsychology at SUNY/Buffalo). A man who never graduated high school, he was so proud when I was accepted to SUNY/Buffalo for a PhD program that he paraded my acceptance letter around the neighborhood for all of his cronies to see. Dad, I finally did it, just like I told you I would; Dad this is dedicated to you!

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## Chapter 1. Introduction

### Problem statement

**Overview:** The prevalence of developmental disabilities is increasing in the United States and is indicative of serious health problems according to a recent Center for Disease Control (CDC report, 2009). They posit that future research should focus on: delineating and understanding risk factors, changes in acceptance and awareness of various disabling conditions, and intervention strategies to promote maximum development in the population ([www.cdc.gov/features/dsDev\\_Disabilities](http://www.cdc.gov/features/dsDev_Disabilities)).

The CDC reports that 13.7% of children between the ages of 3-17 years fall within the category of “any developmental disability,” with those experiencing the most profound disabling conditions accounting for 1% of that 13.7% population. These proportions appear to be on the rise due to aggressive intrauterine treatments and technological advances allowing premature newborns of extreme low birth weights (<1500g) to survive the early neonatal period. Data from the CDC show that developmental disabilities (DDs) are common: about 1 in 6 children in the U.S. had a DD in 2006–2008. These data also showed that prevalence of parent-reported DDs has increased 17.1% from 1997 to 2008. This underscores the increasing need for health, education, and more specialized social services for people with DDs, as well as more detailed exploration of the lived experience of IWDDs.

**Psychiatric disorders in this population.** Epidemiological studies indicate that individuals with developmental disabilities (IWDD) are more likely to experience psychiatric disorders than the general population (Whitaker & Read, 2006). The prevalence rate for psychiatric disorders for individuals with intellectual disabilities has

been estimated to be as high as 40-50 per cent as compared to the 16 per cent prevalence in the population at large (Gibson, 2009). The Diagnostic Manual-Intellectual Disability (DM-ID) reports lower IQ may be the most significant factor associated with psychiatric disturbances in children (Fletcher, Loschen, Stavarakaki, & First, 2007).

Many factors contribute to this situation. For example, IWDD have decreased opportunities to learn adaptive coping styles such as decreased inhibition in response to stressful events (Linville, 1985). In addition, higher rates of sexual abuse (Swango-Wilson, 2010), low levels of social support (Lofgren-Martenson, 2004), lower socioeconomic levels and increased likelihood of central nervous system damage/language dysfunction (Breslau, Chilcoat, DelDotto, Andreski, & Brown, 1996) also impact manifestation of psychiatric disorders in this population. These demographics indicate a need to focus attention on this population of IWDD and examine the various components that enhance their sense of life quality. IWDD have increased susceptibility to emotional, physical and societal marginalization which amplifies risk to their emotional well-being, development of positive self-concept and overall experience of well-being.

### **Self-concept and Identity Complexity**

**Identity** is a set of meanings that represent the understandings, feelings and expectations that are applied to the self as an occupant of a social position (Cast & Burke, 2002) or a social role (Stets & Burke, 2000) or a social group (Oyersman, Elmore & Smith, 2012). This construct is relational/reflexive in nature rather than internally derived. **Identity complexity** is the set of identities that one recognizes in oneself (myself as a brother, myself as an artist, myself as a disabled person) and is one aspect of

self-concept. **Self-concept** is a multidimensional cognitive structure which is internally derived rather than relational in nature (Bogart, 2014). Hence, **identity development** is a process by which identity complexity is built via social interactions and activities, resulting in an aspect of self-concept. Ergo, more exposures to varied social contexts and activities result in more varied identities formed in relation to those exposures.

**Identity complexity** refers to the situation in which one's self-concept includes multiple identities (or aspects of identity) related to varied social contexts.

For IWDD, the opportunity to experience a variety of social contexts may be constrained due to their physical and medical requirements. Participants are constrained by the need for regular medication regimes, schedules for activities of daily living (ADLs) which can interfere with their involvement in varied social contexts. Identity complexity (i.e. the presence of multiple aspects of identity due to exposures to varied social, recreational, vocational, etc. contexts) is posited to protect individuals (IWDD included) from threats of stigma, loss and other social and environmental challenges. Maintaining multiple identities (and subsequently complex self-concept) reflecting various social, recreational, religious, sexual, and familial affiliations have implications for emotional defenses and protection against various social and physical environmental challenges (Linville, 1985, 1987; Thoits, 2011). These protections allow individuals to feel safer and have a better sense of well-being and life quality. Identifying mechanisms that enhance the complexity and richness of self-concept may allow social workers and others to develop relevant interventions for IWDD in order to enhance their overall sense of well-being and life quality.

Exposing individuals to enriching, creative environments and activities may enhance and increase the number of identities within their self-concept, and subsequently may serve to increase their overall identity complexity. As noted by Linville (1985), when a person has limited number of identities associated with less complexity of affiliations, an assault to that particular identity will be associated with a greater trauma for the person. Identity complexity (multiple valued identities within the self-concept) can act as a “buffer” to threats such as loss associated with various roles that the person enacts. Loss of a role such as a job (i.e. person gets laid off or fired), as a pet owner (dog runs away), or as an athlete (person becomes disabled) may be ameliorated as the person maintains other identities within his/her self-concept that are important and of a positive valence to him/herself.

Access to a facilitated arts program may provide an additional context for an IWDD to participate and express him/herself. In this research, a facilitated arts program offers an additional venue in which IWDD can gain exposure to new identities (as an artist) and expand (or make more complex) their self-concept, enhancing identity complexity. Artists in the Arts Access program from the medical center where this research study was done have their works of art displayed in many different public venues and some have sold their works for hundreds of dollars. In this study, I suggest a process (grounded in these data) by which self-concept develops and may result in identity complexity. This study with individuals who have multiple, physical and developmental disabilities (who have access to a facilitated arts program) may provide important information for social work practice with this population.

### **Arts Access Program**

Traditionally, art therapy has been utilized in mental health domains as a method to improve and enhance physical, mental, and emotional well-being of individuals (Burton & Stevenson, 2010; Regev & Guttman, 2005; Reynolds & Pryor, 2003, 2006; Stuckey & Nobel, 2010; Sulewski, Boeltzig, & Hasnain, 2012; Svensk, Oster, Thyme, Magnusson et.al., 2009; Taylor, 2005). Art therapy utilizes the creative process to facilitate communication to assess, diagnose, and treat children and adults. In effect, therapists guide and control the art creation process as a means for treatment purposes. In contrast, the Arts Access' process is *not* utilized for treatment or diagnosis. This is a fine arts program with the sole intent of facilitating the artistic process which is controlled in entirety by the 'artist,' an individual who is unable to physically create the artwork, but who makes every decision related to the production of the art. The 'facilitator' is merely the hands affecting the artistic vision of the person utilizing the process. Facilitators become familiar with the 'artist's' communication modality, be it head nod, use of a communication device. The facilitator provides each artist with an array of choices of materials, strokes, and textures for the piece of art. Every choice in the creation of a work of art is by the artist's direction. The result of this process is a creative product characterized by the specific point of view of the artist creator (the IWDD). Pilot work is underway to test the integrity of the process (i.e. to ensure that each individual's artistic creation is marked by their unique style and is differentiated from the professional artist who serves as facilitator) (Steiner, Reed, Agamanolis, & Gothard, unpublished protocol, 2011).

**Specific aim and research questions:**

The primary aim for this study is to examine a) a process for development of identity complexity in IWDD and b) the impact of changing social contextual environments (activities and roles to which they are exposed and assume, respectively) on identity complexity and ultimately on self-concept and life quality. A unique aspect of this project is that it includes an exploration of how exposure to, and participation in, a facilitated arts program may affect identity complexity and therefore self-concept. This aim is aligned with the aforementioned CDC directives for future research with this population. Research questions to be addressed in this study include:

- 1) How do individuals with disability make meaning of their own identity?
- 2) How does the disability identity manifest itself within IWDD's identity structures and how does this impact their overall sense of well-being and life quality
- 3) What are the roles and social contexts that create or enhance identity complexity and how might this affect an IWDD's overall self-concept and sense of well-being and life quality?
- 4) What is the impact of creating art on self-concept for IWDDs in a facilitated arts program?

### **Theoretical Rationale and Framework**

In summary, individuals without disabilities have more freedom to select and engage in a variety of activities of their own choosing. However, for individuals who have multiple physical and/or cognitive disabilities, the ability to access and become involved in a full array of self-selected activities may be constricted due to physical, medical and social barriers. This, in turn, may limit their ability to develop multiple identities, and subsequently impact their self-concept.

There are a number of conceptual models that explain identity development and the impact of social contextual factors such as exposure to new activities and roles. In addition, various theoretical frameworks attempt to explain how limited access to opportunities in society means that IWDD become marginalized in ways that perpetuate misperceptions which can lead to stigmatizing IWDD. In contrast, exposures to such opportunities may allow IWDD to adopt valued roles in society (enhancing identity complexity) while also showing typical members of society that IWDD have valued roles (decreasing marginalization and stigma). Ultimately, these factors may contribute to the previously mentioned social/emotional consequences on the micro level (i.e. identity development and complexity). No relevant frameworks attempt to combine these processes for IWDD. The next section of this introduction will outline identity development frameworks and consider the role of stigma and stereotype. Following that, I will propose a conceptual model combining the relevant constructs from each that frames this investigative inquiry.

**Identity development.** Identity development is a phenomenon shaped by exposure to different experiences. Many theorists have offered suggestions for factors governing identity development. Erikson (1959) proposed eight stages of psychosocial development as governed by mastering certain crises at pivotal stages of growth. In particular, the adolescent stage of identity vs identity confusion presents a developing adolescent with the task of integrating their newly achieved mastery with their current self-concept and dreams for their future adult sense of self (Widick, Knefelkamp, & Parker, 1975). According to Erikson (1959) identity consolidation comes as a result of consolidating the identities adolescents develop as they experiment with varied roles.



They achieve mastery of abstract levels of thinking and become able to consider and analyze themselves and their identities to feel consistent and whole rather than sense diffusion and a lack of a continuous identity.

There is a progressive element to Erikson's process in that each stage builds on successful mastery of previous stages. Failure to achieve resolution of a particular stage is proposed to lead to incomplete resolution of succeeding stages. For IWDD, lack of appropriate role models and abbreviated achievement in mastery of earlier developmental tasks due to physical (and sometimes cognitive) disability may slow and alter the pattern of identity development as suggested by Erikson.

Other obstacles to positive identity development in IWDD arise from social contextual factors (Shakespeare, 1996). IWDD are socialized to think of themselves negatively, as "inferior" to people without disabilities by virtue of the medical model's emphasis on impairment. Further, as denoted by Shakespeare (1996), IWDD are segregated from each other and subsequently from role-models and "collective support" (p. 104).

Several theorists posit that identity development occurs in response to experiences with various social contextual environments (Crocker, Major, & Steele, 1998; Markowitz, 2005; Shakespeare, 1996). Markowitz (2005) proposes that self-concept arises from perceptions about how others view and respond to the self as a social object. Yang, Kleinman, Link, Phelan, Leed, & Goode (2007) explore the impact of stigma on the development of self-concept. They make connections between 'what matters most in life' to individuals and how the impact of stigma may threaten those every day activities. This concept will be further expanded upon in the following section.

**Stigma and stereotyping processes.** Stereotypic attitudes and beliefs about disability keep IWDD from full participation in typical social settings. Stereotypes can be negatively or positively oriented. In the case of disability, most stereotypes are comprised of negative beliefs (myths) and misperceptions about the population. While much attention has been paid to physical barriers consisting of stairs without a ramp for wheelchairs which would prevent access to various settings, social barriers have been a neglected foci for accommodations. Stigma associated with having disability and stereotyping processes towards IWDD create barriers of an emotional nature consisting of ostracism and rejection within wider social networks (Obsorn, 2006)

Language and discourse to label IWDD in various diagnostic categories may serve to exacerbate negative attributions emanating from self and others (Foucault, 1977; Nario-Redmond, 2010; Phelan, Link, & Dovidio, 2008; Scheff, 2007; Yang et.al., 2006). Research has shown that in contrast to typical individuals, IWDD are characterized as “dependent, incompetent, and asexual” (Nario-Redmond, 2010, p. 471). Despite the heterogeneity underlying the condition of ‘disability,’ society tends to maintain negative implicit stereotypes towards this social group as a whole (Robey, 2006).

Disenfranchised groups such as IWDD have historically been devalued and placed in lower perceived social categories (Heider, 1958; Phelan et al., 2008). As society views this group as consumers, not productive members contributing to the community, this further decreases their value in the eyes of non-disabled persons. This devaluation from others can then become integrated into IWDD’s self-concepts.

**The Social Model of Disability.** The Social Model defines disability as an impairment of society to accommodate individuals with special needs; this is in contrast

to typical society which places the onus on an IWDD to fit in (Burchardt, 2004; Oliver, 1996; Shakespeare, 2006). The main focus of the social model is on breaking down societal barriers that prevent individuals from fully participating in the community (Race, Boxall, & Carson, 2005; Taylor, 2005). The Social Model provides a foundation to empower individuals with disabilities to network, develop advocacy groups and reframe the way that society views and accommodates those who are disabled.

The social model explains impairment in terms of the characteristics of society's barriers. Barriers which disable people with impairments can consist of: obvious things like inaccessible buildings and inaccessible transportation; barriers can also consist of prejudice and stereotypes, inflexible organizational procedures and practices, and inaccessible information. Within the social model, these barriers are understood to be the things that impair the IWDD, not the physical differences any IWDD may have.

Discrimination may mean that IWDD spend their life struggling with low self esteem due to ostracism and social exclusion. Further, discrimination may pave the way for persons in society to ignore physical, contextual and social barriers. This subsequently can limit IWDD's exposure to, and full participation in, self-selected activities. This then has implications for IWDD as they have fewer opportunities to gain exposures to valued roles and activities, diminishing identity complexity and lessening IWDD's sense of well-being and life quality.

**Social Role Valorization.** Social Role Valorization (SRV) is a prescriptive theory initially articulated to support disenfranchised groups. Having evolved from the Theory of Normalization, SRV is concerned with the enhancement of a person or group's social images and competencies (Wolfensberger, 1983) that are at risk of social

devaluation (Osborn, 2006) through lack of accommodations. Devalued roles, and the part played by services in perpetuating them, may result in devalued people being cast in negative social roles, (Race et al., 2005) and/or “becoming vulnerable as the objects of abuse, violence, and brutalization” (Osborn, 2006, p. 5).

SRV prescribes accommodations (physical and social conditions) to the environment to enable IWDD to actively participate in society with the intent of promoting positive perceptions of the IWDD by others. One would predict that promoting positive perceptions of IWDD might facilitate accommodations for access to education and services. Hence, the more valued the social image of IWDD, the greater the accommodations in the environment. People are much more likely to experience the “good things in life” if they hold higher social roles in society (Osborn, 2006). So, the task that SRV sets out for society is to create environmental accommodations for IWDD in order to increase the value of their perceived social roles.

The Social Model of Disability (Oliver, 1996) and Social Role Valorization (SRV) (Osborn, 2006; Wolfensberger, 1983) provide a framework for the creation of a new conceptualization in disability practice. In order for IWDD to be successfully integrated into society, the coordination of these two models provides support to examine effective accommodations. For example, policies that mandate society to provide handicapped ramps, elevators in buildings, and wheelchair accessible transportation provide opportunities for IWDD to independently navigate their communities and participate in vocational and recreational activities which previously were inaccessible. With the advent of new assistive technology (AT), IWDD are able to participate in previously unimagined domains (Lancioni, Singh, O'Reilly, Oliva, & Basili, 2005).

While these two models have been compared and contrasted in the literature, arguments have been made for the utility of a combined approach (Race et al, 2005). I suggest the Social Model of Disability may be viewed as the conceptual framework within which SRV might define the physical and social modifications that need to be made in the social environment in order for these accommodations to be successfully enacted.

The Social Model defines societal modifications on a macro level while Social Role Valorization extends these modifications to create access for the population within a particular community (at the meso level). This process speaks to technological advances (assistive technologies- AT) which promote a previously unattainable level of self-expression, autonomy and community integration for IWDD (Arthur, 2003; Sigafos, O'Reilly, Ganz, Lancioni, & Schlosser, 2005). The American Disabilities Act of 1990 proclaims:

Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of society” PUBLIC LAW 106-402.

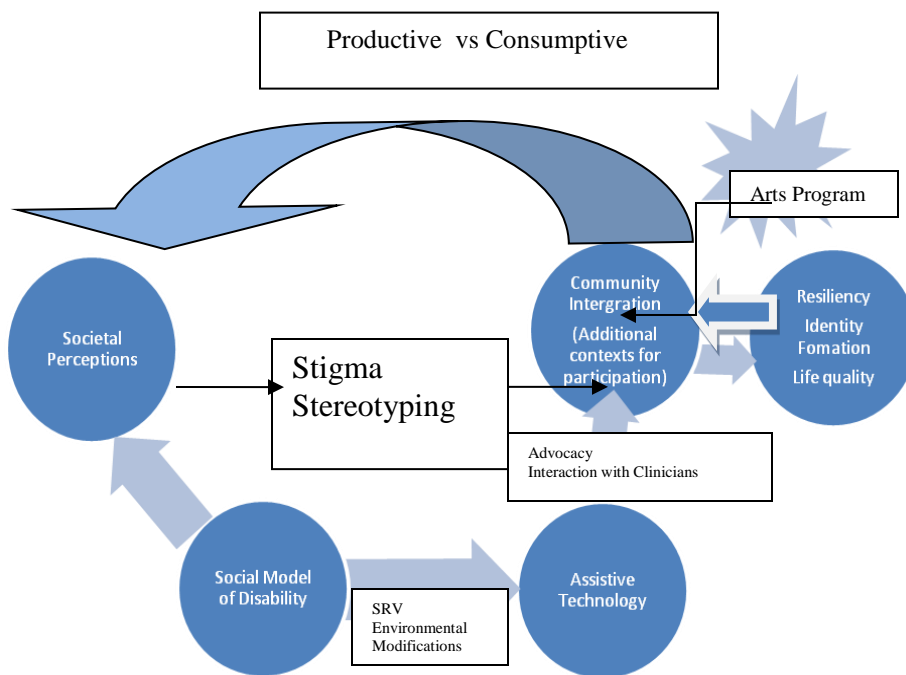
As a result of such social justice initiatives and innovative technological advances, IWDD may finally be provided with means to access and participate in the full range of life experiences enjoyed by any member of society.

***Integrative Conceptual Model.*** The manner in which such processes affect IWDD’s self-conceptualizations has not yet been explored in the literature in light of the rapidly changing technological advances (Arthur, 2003; Sigafos et al., 2005). By

instituting a Social Model understanding of accommodations and implementing AT and other enabling technologies in practice based settings, we might facilitate more self-expression and participation in social life (at the micro level). Few studies have explored the impact of utilizing AT on the enhancement of self-concept and life quality.

AT may help to minimize the gap between an individual's ability to function in his/her environment and the social supports needed to facilitate the adjustment process. Marginalization of IWDD contributes to maintenance of the status quo for devalued groups, so successful integration into society is critical for the enhancement of social image and to fight marginalization and stigmatization.. The degree to which social image impacts the individuals' self-concepts, and subsequently the protective value of complex and varied identities, may be integral to IWDD's adjustment process and ultimately life quality.

Thus, a feedback loop develops which defines a process by which enhanced self-concept and identity complexity might facilitate community integration, and vice versa. For example, becoming "an artist" and producing art adds to identity complexity and contributes to the community at large. This circumstance further impacts and enhances societal perceptions, thus increasing social image and decreasing stigma towards the IWDD. A conceptual model depicting these processes is proposed as a framework to guide this investigation (see figure 1).



**Figure 1. Conceptual Model of interactional processes impacting identity formation for IWDD**

### **Implications for Social Work**

IWDD are universally acknowledged as a devalued and marginalized population (Charmaz, 2008). While research exists on the impact of social exclusion on various minority populations, less is known about the impacts of exclusion on IWDD's self-concept and life quality. This study makes the following contributions to the field: 1) exploration of the elements involved in identity development and self-concept in this population, 2) examination of how exposure to a facilitated arts program impacts self-concept, 3) examination of the aspects of life that IWDD identify as adding to their life quality and sense of well-being and 4) consideration of what accommodations appear effective in promoting development of identity complexity in IWDDs. Moreover, results may have implications for clinical interventions, community programming, and community engagement.

## Chapter 2. Literature Review

### Overview

Society has historically had a tendency to stigmatize (Goffman, 1963, 1997) and devalue persons with disabilities (Dole, 2001; Shakespeare, 2008). As a result, various societal barriers impede full involvement of, and contribute to lack of choice for participation in life experiences which in turn limit the social contexts within which individuals with developmental disabilities (IWDD) participate. If we accept the premise that exposures to multiple social contexts facilitate the development of complex identities, this in turn may exacerbate negative self-concept if those exposures are limited by environmental and social barriers (Murugami, 2009; Oliver, 1996). The manner in which this process occurs includes:

- 1) the existence of physical/medical, environmental and social barriers
- 2) limited exposure to varied social contexts by the aforementioned barriers which affects role acquisition and identity formation and subsequently identity complexity
- 3) this may result in a decrease in resiliency afforded by complex identity structures (Deaux, 1993; Thoits, 2011).

These effects are evidenced at the micro, meso and macro levels and have cyclic feedback on each other as outlined in Figure 1 in Chapter 1.

Having presented a brief overview of the importance of exploring identity complexity in IWDD in the previous chapter, this chapter will discuss the evidence based literature comprising the field of identity development, the development of identity complexity and the subsequent impacts on social interactions and social



exclusion/inclusion processes. Ultimately, the case will be made for the role of identity complexity in contributing to life quality and well-being in IWDD. First, I will review general identity formation processes. Next, the concept of multiple identities will be discussed relative to social contextual inputs and their inherent value in contributing to resiliency for IWDD. I will then review the literature pertaining to the development of the 'Disability Identity,' followed by a consideration of how stigma and devaluation may affect self-concept within social contexts. This will be followed by a discussion of the literature examining how being considered an 'other' in mainstream social environments results in IWDD being excluded and the subsequent impact this exclusion has on their self-concepts. Further, the literature surrounding the relationship between self-concept and life quality experiences will be reviewed. This will be followed by a consideration of how involvement in artistic activities impacts self-concept and life quality for IWDD. Prior to this in-depth consideration of the literature, I will provide a brief reminder of how I am defining basic concepts which will be woven throughout the literature.

**Definitions of key concepts.** Identity is defined here as a set of meanings that represents the understandings, feelings and expectations that are applied to the various aspects of self an occupant of a social position (Cast & Burke, 2002) or a social role (Stets & Burke, 2000) or a social group (Oyersman et al., 2012). More specifically, identity complexity is described as a set of identities that one recognizes in oneself (myself as a brother, myself as an artist, myself as a disabled person). This construct is relational/reflexive in nature rather than internally derived. Self-concept is a multidimensional cognitive structure which is internally derived rather than relational in nature (Bogart, 2014). Self-concept is comprised of various identities (social roles,

avocations and vocations), self-esteem and self-efficacy. Identity development is a process by which multiple identities (identity complexity) is built via social interactions and activities, resulting in an aspect of self-concept. Increased exposures to varied social contexts and activities results in an increased number of identities formed in relation to those exposures. Hence, identity complexity refers to the situation in which one's self-concept includes multiple identities (or aspects of identity or social roles) related to those varied social contexts.

### **General Identity Development**

There is a spectrum of literature that views identity formation from a developmental paradigm (Erikson, 1959; Marcia, 1991). Developmental theorists posit that identity formation begins in infancy when an infant first recognizes him/herself as a unique individual. Self-recognition in a mirror has been posited to be early developmental evidence of the understanding of self (Bullock & Lutkenhaus, 1990). These processes continue throughout childhood as the child learns from experiences, with identity becoming more refined and complex. Eventually identity formation processes gain further differentiation in adulthood where focus is directed towards social roles, specifically: avocations, vocations, group affiliations, family relationships, etc.

Erikson (1959) postulated that identity formation occurs as a result of resolving various life crises that occur during different stages of development. Marcia (1991) further elaborated on Erikson's work and proposed that there are two steps governing identity development. First, the individual needs to break off from childhood beliefs to explore alternatives in a different area and second, the individual must make a

commitment to that particular area. Failure to resolve these crises will lead to problems for the individual in adulthood.

This trajectory is complicated for IWDD who have multiple, profound and complex disabilities. These individuals are unable to individuate in a physical sense as they continue to be dependent on caregivers for assistance with all activities of daily living (ADLs) throughout their lives. In addition, further complicating this process are the limitations imposed by various medical, physical and social barriers in experiencing a vast array of social roles which will be further explored in the following sections.

### **Social Psychological Theories of Identity Development**

**Social context paradigms.** Other models of identity development have been generated from a social contextual paradigm. These theories posit that self-concept emerges out of social relationships (Thoits, 1985) and reflect the various social contexts within which a person functions. For example, Sharon Dole (2001) suggests that identity formation in IWDD evolves out of a socio-historical context. She posits that identity formation is a dynamic process which reflects the societal, psychological, historical and developmental parameters from extra-personal and intrapersonal forces. Postmodern theorists echo this sentiment, that multiple identities reflect and are defined in various social contexts and the relevancy of each identity varies based on a particular point in time (McConnell, Shoda, & Skulborstad, 2012; Riddell, Baron, & Wilson, 2001; Wang & Dovidio, 2011).

People define themselves in relation to how they are perceived by others in social situations e.g. a student, an artist, a social worker, etc. Most people retain multiple ‘social identities’ and when enacting such roles become situated in a stratified social

structure. A ‘disability identity’ may be one of many identities that an IWDD may hold (which will be further elaborated upon in ‘Development of Multiple Identities’ section to follow).

***The Development of Multiple Identities.*** Kenneth Gergen (1985) proposed that rather than ‘one self,’ there is a ‘multiplicity of selves’ based upon the context in which an individual finds himself/herself situated at a particular point in time. Some such personas may include: ‘myself as a father’; ‘myself as a teacher’; ‘myself as an artist’; ‘myself as an athlete’ (Deaux, 1993). Different aspects comprise a person’s life experiences and are reflected in this ‘multiplicity’ of selves as associated with a multiplicity of thoughts, feelings and associated psychological attributes.

Jones and McEwen (2000) explored the development of multiple identities in female college students. Their research provided support for the thesis that individuals maintain multiple identities and distinguished between social identities perceived within the self and those that are externally derived (or perceived by others). A follow-up study (Abes, Jones, & McEwen, 2007) examined the fluidity of identity structures and the salience of self-concept within the identity dimensions of their revised conceptual model. Using a grounded theory approach, they explored meaning making with personal and social identities in college students.

Allen McConnell developed the Multiple Self-Aspects Framework of Self-Concept (2011). This framework defines self-concept as a collection of multiple selves which are dependent upon the social context within which they are enacted. He based this work on previous research conducted on the relationship between self-complexity and identity complexity. Maintaining multiple self-concepts is associated with well-

being and is moderated by the individual maintaining control over those selves (McConnell, Renaud, Dean, Green, Lamoreaux, Hall, & Rydell, 2005). Self-concept (or self-aspect as referenced in this research) is heavily context dependent and develops in relation to the pursuit of one's goals. Following from this, it is obvious that goals can change depending on the particular context, or in other words, the context can activate the relevant cognitive aspects (identity/role) of an individual and elicit relevant attributes related to that self-concept. For example, the self-concept of being a mother may be activated in relation to being in the presence of one's daughter and elicit the attribute of nurturance.

Riddell, Baron, and Wilson (2001) report that individuals with disabilities exhibit multiple identities associated with varying self-described attributes. Subsequently, Johnstone (2004) notes that individuals with disabilities do not define themselves in terms of a single description but rather with multiple descriptors in accordance with the previously described literature. Several research programs have adopted this conceptual framework. Salgado and Hermans (2005) conceived of a "dialogical" epistemology of the construction of multiple identities. They posit that an individual's self-concept changes in relation to their various experiences in a dynamic manner. The "dialogical" component is comprised of complex self-concept derived as a function of exposure to external stimuli and the subjective experience of self.

The previous literature suggests that maintaining multiple identities serves to create greater complexity of self-concept. It is further proposed that maintaining multiple identities may serve to increase protection for an individual to loss or trauma. Linville (1985, 1987) speculated on the diverse aspects of self-concept with regards to salience for

the individual's psycho-social interactions and responses. She proposed that individuals who maintain greater complexity in their self-concepts are less vulnerable to various environmental and emotional assaults whereas, less complexity (i.e. fewer identities within their self-concept) may invoke greater susceptibility to depression and/or anxiety. Hence, maintaining multiple identities may serve as an adaptive-protective mechanism for the individual.

A defense mechanism proposed in the literature as protective is that of priming alternate (more highly regarded or socially valued) identities in reaction to perceived prejudice (Wang & Dovidio, 2011). This proposition might have implications for diagnostic and therapeutic interventions to promote an individual's wellbeing when confronted by trauma or loss. For example, Thoits (2011) examined how individuals with mental disorder develop resistance strategies to dealing with mental illness stereotypes. She concluded that among other characteristics, maintaining multiple identities may facilitate the utilization of such resistance strategies to deal with discrimination. Wang and Dovidio (2011) suggest that protective factors (enhancements of self-concept) are associated with priming alternative identities in the face of prejudice. Here again, research suggests that maintaining complex identities may provide positive benefits to an individual when faced with exclusion or ostracism.

***Social Identity Theory (SIT).*** Tajfel and Turner (1979) theorized that people are motivated to maintain and enhance positive self-images and that identification with groups is a primary element underlying this motivation. This theory is dubbed Social Identity Theory (SIT). People are motivated to identify with groups they perceive more positively which further enhances their own positive sense of self. Research supports the

notion that people tend to identify with those groups which they perceive as occupying a higher social category than those perceived to be of lower status (Tajfel & Turner, 1979). In a sense this seems to echo on a group level, the constructs outlined on an interpersonal level in the Theory of Interdependence (to be described in a following section: Social Interactional Theories).

Roccas (2003) expanded on this premise by exploring the effects of higher social status on identification with multiple groups. In keeping with the basic premise of role theory, individuals maintain multiple roles in connection with their associations with multiple group affiliations. Some of these groups are perceived as having higher vs lower status in relation to others. Roccas found that individuals tend to identify more strongly with groups perceived as having higher social status if they simultaneously hold membership in a lower status group. For example (and in relation to this study) if a person is affiliated with disability (lower status group) and also maintains affiliation as an artist (higher status group), that person may place more emphasis on the artist group identity. Here again, maintaining multiple group affiliations may be protective for individuals.

### **Disability Identity Formation literature**

People with disabilities describe themselves in a variety of ways (as do people who do not have disabilities) and may experience the condition of being ‘disabled’ as a source of pride and/or shame (Johnstone, 2004; Shakespeare, 2006). Johnstone (2004) observed that some individuals have placed the disability identity “in the foreground of their identities.” Disability identity has been posited to be a socially constructed phenomenon by many disability scholars using various marginalized populations’

frameworks, such as feminist theory, gay theory, minority theory, etc. For example, Susan Wendell (1996) views disability and identity through a feminist lens. She proposes that disability is derived from a gap in a person's ability to function within the parameters of a male-oriented society. Wendell's conceptualizations are in accordance with the philosophy emanating out of the Social Model of Disability i.e. the conceptualization that disability arises as a function of society's unwillingness to create accommodations in the environment to narrow the gaps between those who are 'able' to function adequately and those who are not, due to whatever condition (be it physical, gender-related, medical, psychiatric, etc.).

In a different manner; McDermott and Varenne (1995) illustrate several examples of how 'dis' ability arises out of inability to function based on arbitrary cultural foci. They discuss from an anthropological perspective a fictional world created by H.G. Wells. Wells describes an isolated community where everyone is blind and hence the environment is adapted for a non-seeing population to navigate. Language is culturally derived as there is no visual specific vocabulary. Sighted people are disabled by the lack of light.

In reality, such an environment is encapsulated by the deaf community on Martha's Vineyard where there is an extremely high percentage of genetically inherited deafness. In this case, the community (and culture) evolved around deaf people including their own language, American Sign Language (ASL) and all were fully integrated into the social community at large. In fact, it follows that perhaps an individual without a hearing impairment might indeed find themselves to be 'dis'abled in a community established to meet the functional capacities of a population of individuals with hearing impairment. In



a community that utilizes ASL for communication, a hearing person who does not know sign language would surely be at a disadvantage. McDermott and Varenne argue that the conceptualization of ‘disability’ is a social construct and does not occur in a socially isolated vacuum. A socially derived construction such as ‘disability’ may be a necessary antecedent in the development of the ‘disability identity’.

Christopher Johnstone (2004) supports the notion that the disability identity is a personal construction emerging from social and cognitive processes. Johnstone supports Shakespeare’s thesis that IWDD generate and maintain a disability culture which becomes central to their self-concept. He suggests that when delineated by others, this ‘disability identity’ can lead to stigma and become constrictive, but when self-ascribed, is perceived as empowering and liberating by the individual. Becoming identified with a group sharing commonalities can pave the way for advocacy/support, accommodations and breaking down preconceived stereotypes.

The premise that disability is not a “negative” conceptualization is further explored by Donna Reeve (2002). In a conceptual treatise on the subject, she suggests that there is an empowering aspect of embracing the disability identity and refers to it as a “coming out” as a person with a disability, much like in gay culture. She supports Wendell’s thesis that disability experience is perceived differently depending on the form of disability. Shakespeare (1996) on the other hand challenges that comparison. He proposes that the experience of being born with disability is quite different from the homosexual experience of “relinquishing a non-disabled identity and accepting an identity as other” (p.104). Global assertions must be made with caution.

Shakespeare (1996) also delineates a social constructionist perspective supporting the creation of a ‘disability culture’ as an alternative path for IWDD seeking an autonomous identity to challenge preconceived stereotypes. He defines an identity development process that occurs at interconnected political, cultural and personal levels. While of an overall positive nature, this process is fraught with difficulty and complexity and is both internally and externally derived.

The idea of identity formation being a reflexive process between self and society is elaborated on in an examination of identity theory by Stryker and Burke (2000) and is reflected in Figure 1 (in Chapter 1). This becomes a key component of this investigation. Research supports the premise that engagement in disability rights activism is associated with high levels of disability self-identification (Hahn & Beaulaurier, 2001; Hahn & Belt, 2004; Swain & French, 2000; Whitney, 2006; Wilczenski, 1992) and coincides with literature on collective/social identity theory (Tajfel & Turner, 2004). Maintaining a strong ‘disability identity’ may have protective implications for group inclusion, advocacy and support.

### **Social Interaction Theories**

**The Theory of Interdependence.** The iconic Theory of Interdependence (Thibaut & Kelley, 1959) places emphasis on the role of social interaction experiences of individuals in developing their value orientations (Van Lang, DeBruin, Otten, & Joireman, 1997) and sets the stage for examining the impact of interpersonal relationships on life quality and sense of well-being for IWDD. Reynolds, Oakes, Haslam et. al. (2000) suggest that The Theory of Interdependence addresses concerns associated with stereotyping as affecting individuals’ ability to achieve power. Interactional patterns

around issues of power and control of resources are pivotal aspects of this theory (Thibaut & Kelley, 1959).

According to Susan Fiske (1993) stereotyping operates for the purpose of those in power to maintain control over those considered to be of lower importance in the social hierarchy. Those individuals are devalued, disenfranchised, and marginalized people such as the poor, racial/ethnic minorities, women, homosexuals and/or individuals with disabilities (more so for those with physical/visible disabilities). Stereotypes imply false impressions that perpetuate negative attitudes and exploitation (Reynolds et. al. 2000). The goal is the development of interdependent behavior which is defined as achieving an ‘individuated impression’ of others. This process involves a considerable amount of motivation and ‘attentional investment’ by individuals who perceive themselves to be in higher social categories (Kelley and Thibaut, 1978; Reynolds et. al. 2000).

Stereotyping places individuals at a lower status in the social structural hierarchy; hence, devaluing IWDD in the eyes of individuals without disabilities which paves the way for myths and misperceptions. Swango-Wilson (2010) suggests that perceptions of IWDD within these social categories are as ‘child-like’ and naïve i.e. infantilization (Robey, Beckley, & Kirscher, 2006) and asexualization (as a form of stereotyping); of the population. These stereotypes create barriers for IWDD in (1) obtaining education, (2) learning appropriate social skills to increase social acceptability, and (3) increasing vulnerability and decreasing their ability to protect themselves from victimization and abuse (Nosek, Hughes, Taylor, & Taylor, 2006).

How do individuals within stratified hierarchies of social categories in a social environment choose to depict those in other social categories? As previously mentioned,

Thibaut and Kelley (1959) suggest that they may either: rely on social categories; or take more effort to attribute individualized judgments in order to achieve higher degree of accuracy (Reynolds et al., 2000). Individuals in higher stratified categories need to be motivated to ‘individuate’ those in perceived lower status categories. This process is time and energy consuming and if there is not sufficient perceived net gain in outcomes to motivate people to expend those resources, they will not engage in that process, hence perpetuating the maintenance of the problem.

Crisp and Turner (2011) also identify motivation as a key element in engaging individuals in higher social categories to “resolve stereotypical inconsistencies” (p. 242) (which I equate with individuation) of those in lower perceived social categories. A mechanism of intervention prescribed by the Theory of Interdependence would be to enhance perceived mutual outcomes in order to facilitate the attentional time and energy required to individuate IWDD hence, changing attitudes on IWDD in the mainstream population. Crisp and Turner propose that mere exposure to social and cultural diversity serves to combat stereotyping processes by exposing perceivers to inconsistencies with their preconceived stereotypes of the population. The caveat here is that those perceivers must be motivated to resolve those inconsistencies.

**Attribution Theory.** The Theory of Interdependence laid the ground work for the development of Attribution Theory (Kelley, 1967). Attribution Theory examines the role of causal attributions to a person’s behavior in influencing emotional responses of others to that behavior and subsequently in predicting helping behaviors (Weiner, 1983). The role of causal attributions has also been examined in relation to perceptions of stigma (Corrigan, Ludin, Wasowski et.al., 2000; Towler & Schneider, 2005, Weiner, Perry, &

Magnusson, 1988). Weiner et.al. (1988) tested Attribution Theory to different stigmas (physical and mental/behavioral) and discovered different reactions depending on the stigma. Physical stigmas elicited more positive attitudes while mental/behavioral stigmas elicited neglect and more negative attitudes.

For the participants in this dissertation research, both physical and behavioral stigmatizing processes are at work. This further exacerbates the negative attributions that others without disabilities may maintain toward them and subsequently the negative ensuing consequences. For example, in terms of asexualization, the stigma attached to having a developmental disability may affect the perceptions of educators or health care providers and result in neglecting or blocking access to education, health care services and facilitation of IWDD in experiencing their sexuality. Both of these theories (Attribution Theory and the Theory of Interdependence) provide justification for the need to identify motivating agents for others without disabilities to exert time and effort to individuate those individuals who have stigmatizing attributes.

**Stigma/alienation.** Erving Goffman identifies and defines ‘stigma’ as an “attribute that is deeply discrediting” in his seminal work on the topic (Goffman, 1963; p. 3) which contributes to the stigmatized individual becoming tainted and discounted by others. Goffman defines three types of stigma: those of character traits, physical stigma relating to physical deformities of the body and the stigma of belonging to a devalued race, nation or religion. Pertinent to this discussion is the stigma related to physical deformity as seen in those with visible disabilities. In addition, as the following excerpt from Goffman’s “Stigma, Notes on the Management of a Spoiled Identity” elucidates,

concepts from social identity theory seem to be operating here as well. According to Goffman (1963, p 3):

While a stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind--in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive [...] It constitutes a special discrepancy between virtual and actual social identity. Note that there are other types of [such] discrepancy [...] for example the kind that causes us to reclassify an individual from one socially anticipated category to a different but equally well-anticipated one, and the kind that causes us to alter our estimation of the individual upward.

Further exacerbating stigma, labels and professional rhetoric have significant impact on the perception of social acceptability for IWDD and expectations for their performance and societal integration (Paterson, McKenzie, & Lindsay, 2012; Scheff, 1966). Historically, individuals with developmental disability are referred to as ‘intellectually disabled or developmentally disabled,’ ‘mentally retarded’ or ‘cognitively impaired’. The politically correct way of addressing the condition in current society is ‘individual with disability’ adopting a ‘person-first perspective’ i.e. you are a person first not a disability (Blaska, 1991). Moreover, the label ‘retardation’ has assumed a negative connotation in contemporary society as illustrated by the recent “say no to the R word campaign” promoted by the New Jersey Self Advocacy Project (NJSAP) and nationally

recognized organizations such as the American Association of the Mentally Retarded (AAMR) evolving into American Association of Individuals with Developmental Disabilities (AAIDD).

An additional element in the relationship between discourse and shaped perceptions about individuals resides in professional evaluative processes. Aspects of the classification systems shape the ways clients are perceived (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989; Scheff, 1966) as well as their self-perceptions (Thoits, 1985). Determinations of cognitive impairment based solely on I.Q. testing are not sufficient in providing an accurate understanding of the individual's abilities.

The ICIDH (International Classification of Impairments, Disease and Handicaps) recognizes that the entire social contextual environment within which an individual functions needs to be taken into account (O'Brien, 2001; WHO, 2011) when assigning categories for IWDD. Social context factors include those social conditions (e.g. socioeconomic status) may predispose marginalized populations to become devalued and stigmatized by those in power. Research indicates that children with disabilities raised under poor economic circumstances have significantly increased risks of adverse outcomes such as mental and physical health issues compared to peers who are nondisabled (Emerson, Graham, McCulloch, Blacher et.al, 2009).

***The relationship between stigma and self-concept.*** Stigma has been widely referenced in the literature as negatively impacting one's self-concept and sense of well-being (Abraham, Gregory, Wolf, & Pemberton, 2002; Dagnan & Waring, 2004). IWDD are aware of stigma from others and internalize their perceptions of being negatively perceived by others which become negative core beliefs IWDD maintain about

themselves within their self-concepts. Research on stigma of individuals with intellectual disability indicates that stigma predicts self-esteem. People who perceived themselves to be the targets of stigma, felt more negatively about themselves (Paterson et. al, 2012).

***The benefits of social relationships in combating stigma.*** It is clear from the previous discussion that IWDD are targets of stigma and stereotyping processes by some others who are non-disabled in social environments. These processes negatively impact their self-concept and sense of well-being. There is a wide body of evidence indicating that social relationships have positive benefits related to one's sense of well-being, both in emotional and physical domains and may combat the negative impacts of stigma and stereotyping processes (Cohen & Janicki-Deverts, 2009; Ertel, Glymour, & Berkman, 2009; House, Umberson, & Landis, 1988; Thoits, 1995, Umberson & Montez, 2010). Further, maintaining strong social supports buffers trauma associated with stress (Thoits, 1995; Uchino, 2004).

Thoits (2011) explores mechanisms linking social ties and support to physical and mental health and concludes that maintaining strong social connections with significant others mitigate physical and emotional impacts of stressors. She identifies a process she terms 'role-based purpose' which contributes to a sense of control and belonging. Maintaining role identities, which are social ties in relation to social relationships, governs one's behaviors when enacting a particular social role. In addition, maintaining social connections provides a person with meaning and purpose in life.

Thoits (2011) references Rosenberg and McCullough's (1981) conceptualization of "mattering" which is in essence, the knowledge that one is of importance to another person. In another work that year (2011) Thoits tests these theoretical propositions by



analyzing survey data derived from cardiac patients and their hospital volunteer visitors. The conclusion derived from this analysis is that the more salient the role identity, the greater the sense of purpose and meaning which then leads to enhanced sense of well-being.

**Social exclusion.** It is not difficult to envision how stigma and stereotyping processes may contribute to IWDD feeling socially excluded from populations without disabilities or to further extrapolate as to the negative impact that this might have on their self-concepts. Maintaining social connections positively impacts sense of self. Ergo, being excluded from social interactions would be hypothesized to have the reverse effect, that of negatively impacting self-concept. Research has borne out this hypothesis. Social exclusion has been demonstrated to impair self-regulation (Baumeister, DeWall, Ciarocco, & Twenge, 2005; DeWall, Twenge, Gitter, & Baumeister, 2009; Twenge, Catanese, & Baumeister, 2002), life quality (as defined by physical health, social relationships and psychological parameters) (Bayram, Bilgel, & Bilgel, 2012) and emotional regulation (Buckley, Winkel, & Leary, 2004; Capozza, Trifiletti, Vezzali, & Favara, 2013).

IWDD who manifest visible disability are particularly prone to this type of social exclusion and rejection. Consequences of being socially excluded are also associated with emotional distress (Baumeister, Brewer, Tice, & Twenge, 2007). In order to further determine the association of identity complexity and exclusionary processes on an individual's well-being, an examination of the various constructs used to represent life quality is warranted.

### **Life quality and IWDD**

Koch (2000) questions preconceived quality of life assessment tools that may be based on erroneous assumptions arising out of the medical model. This model assumes that the extent of disease burden defines the person's ability to benefit and enjoy positive life experiences. However, qualitative and personal reflections by IWDD report higher self-perceived life quality than the various assessment instruments would indicate. This leads us to wonder how life quality is defined by those with disabilities as opposed to a preconceived ideology of what constitutes a universal quality of life construct. Koch makes a case that by solely focusing on physical impairments, typical assessment tools do not account for social and community accommodations and adaptations to facilitate a person's perceived life quality.

Scheff and Fearon, Jr. (2004) further expand on the merits of standardized assessments or lack thereof, in attempting to quantify an abstract construct such as 'quality of life.' According to these scholars, self-esteem surveys have long been utilized as the hallmark of measurement for quality of life as a measure of positive outcomes for an intervention. They critique the literature using self-esteem scales. Their claim is that these scales are aconceptual and atheoretical (deal only with surface variables and may in effect miss the main motives of behavior). Further, the quantitative evaluations do not report effect size so the findings are difficult to fully evaluate. Given large sample sizes, .001 significance can be achieved when only a tiny proportion of the variance is explained. In addition, when evaluating IWDD with cognitive deficits, proxy reports are not necessarily reflective of the individual's experiences. Other researchers corroborate this concern (Koch, 2000; Schalock, Brown, Brown et. al., 2002). Measures based on

outcomes of such large sample sizes need to be sensitive to the application principles utilized.

Perhaps for the above outlined reasons, most research in the field has been conducted using a phenomenological framework (Burton & Stevenson, 2010; Regev & Guttman, 2005; Reynolds & Prior, 2003, 2006; Taylor, 2005). Life quality is a subjective conceptualization that has different meanings to different people under different circumstances. Phenomenological approaches allow the researcher to grasp the particular meaning of an individual's experience from their perspectives and reflect the particular environmental/social context of interest (Patton, 2002). Patton suggests that it is in discovering the subtle nuances of a person's experience that we can best understand a particular intervention when dealing with such an individualized experience as life quality.

**Life quality and sense of well-being of IWDD.** Rather than focus on quality of life parameters as assessing IWDD's sense of well-being, Rey, Extremera, Duran, & Ortiz-Tallo (2013) place focus on the role of emotional competence on the 'subjective well-being' of individuals with intellectual disabilities. The sense of subjective well-being (SWB) relates to experiencing positive emotions such as happiness or thinking positively about their lives such as maintaining a cognition of life satisfaction. Using these constructs, they examined the various factors that impact SWB and quality of life.

Emotional competence (EC) is one of a panorama of functional life skills that are considered necessary for people with intellectual disabilities to adapt to routine life experiences. Emotional competency is defined as the ability to react appropriately to affective information or more specifically the ability to regulate one's emotional

reactions. Other life skills, in addition to EC include: social, communication and affective skills. Not achieving proficiency in these skill sets is proposed to lead to difficulty in achieving adaptation to everyday life and not living up to their optimal potential, which might impact self-efficacy, a component of self-concept.

Other research identified factors that people with learning disability associate with having happy and satisfying lives. These factors include: social relationships (especially relationships with family), choice and independence, involvement in interesting activities and maintaining valued social roles (such as having a job) (Haigh et al., 2013). Access and financial barriers were reported by participants in this study as preventing them from obtaining those good things in life (Haigh et al., 2013). As previously mentioned the ‘good things in life’ is a conceptualization articulated by social role valorization (SRV) and the Theory of Normalization as described in Chapter 1. According to SRV, all people, including IWDD are entitled ‘to the good things in life’ and as a result this has become a variable to measure successful adaptation of IWDD.

### **Impact of the arts on identity complexity and life quality.**

Art is a language by which the human mind gives utterance to its own integrity. It holds the two main sides of mind, objective and subjective, in their appropriate unity, and it articulates that unity in an image for intuition [Hofstadler, 1969, p. 83].

This quote is from ‘On the Consciousness and Language of Art in New Essays in Phenomenology’ (1969) that explores the experience of meaning through perception, discourse and ultimately artistic representations. There is some debate over the expressive quality of art and the meaning conveyed in art from a phenomenological

perspective. This is derived from an inherent ability on the part of the perceiver to assign their own meaning to the artistic representation set forth by the creator. Does the linguistic expression of meaning coexist with experience? How might this premise be related to artistic expression? What is the experience and meaning for such liberation of expressivity for individuals with disabilities who are provided with a mechanism to express themselves in this manner? Susan Wendell posits that there is a need for “accommodations of pace and expectations” when dealing with IWDD and this premise speaks to the Arts Access mission statement in creating a fully ‘accessible society’ for those with disabilities to navigate (p. 55).

The benefits of engaging in creative artistic expression have been well-documented in the literature in relation to chronic illness and disability (Burton & Stevenson, 2010; Regev & Guttman, 2005; Reynolds & Prior, 2003, 2005; Stuckey & Nobel, 2010; Sulewski et al., 2012; Svensk et al., 2008; Taylor, 2005). A comprehensive literature review by Stuckey and Nobel (2010) found that engaging in creative artistic activities has positive impacts on health and counteracts the negative effects of stress and depression. Their review focused on chronic illnesses such as cancer and renal failure but did not address those individuals with physical and developmental disabilities.

A randomized controlled study conducted by Svensk, et.al. (2008) reported that breast cancer patients who received art therapy sessions before their radiation treatments manifested improvements in overall health, quality of life and psychological health. Reynolds and Prior (2003, 2006) utilized qualitative methods to enhance understanding of how ‘art-making’ serves to maintain resilience in the face of disability. In their narrative study of women with cancer, they found that art provides a mechanism to help

individuals with disability maintain their social and personal identities. Art-making, in this investigation, was conceived of as purely a leisure activity, not utilized in a therapeutic context. Their conclusions suggest that people with disability need to engage in meaningful activities to enhance coping in the face of catastrophic illness.

In essence, art offers a powerful means of regaining positive self-concept when health is compromised. We can extrapolate from this premise that there appears to be a consistent connection between exposure to, and participation in, creative and stimulating venues and identity complexity and life quality. Hence, while there is abundant research on art's beneficial impact on individuals with physical and mental illness, there is scant evidence surrounding the benefits of engagement in the arts on individuals with multiple physical and developmental disabilities. One of the objectives of this study is to address this gap in the literature.

### **Summary of Literature**

Individuals with chronic disability are the fastest growing minority group in the world today and they are susceptible to oppression, devaluation and marginalization as are most minority groups. This impacts IWDD's self-concept and quality of life experiences and speaks to the need to understand the underlying experiences surrounding being disenfranchised and marginalized. In addition, existing in a lower perceived social category exacerbates the susceptibility of IWDD to become subjugated to stereotyping and stigmatizing processes.

The literature presented in this chapter outlines the basic processes for identity development for persons in general and for IWDD in particular. I have outlined a rationale on the benefit of maintaining multiple identities within one's self concept, and

specifically the formation of the ‘disability identity’ in response to cultural and oppressive stereotyping. This foundation sets the stage for an exploration into the development of complex identities of IWDD. In addition, emphasis is placed on how exposure to varied social contexts may impact IWDD’s evolving identity complexity and the ultimate benefit this may have for achieving a self-perceived life quality.

Individuals are social in nature and desire group acceptance. The tendency of those situated in perceived higher social categories to ostracize and exclude those perceived to be in lower social categories has implications for the health and well-being of those individuals. Identifying mechanisms to combat stereotyping and stigma as well as defining ways to enhance self-concept may serve to buffer the negative consequences resulting from social exclusion. Complex self-concept made up of multiple and valued identities that reflect involvement in varied social contexts can serve as a protective buffer against other more negatively perceived personas which lead to ostracism and the negative emotional ramifications associated with such social exclusion.

### **Chapter 3. Methods**

#### **Introduction:**

I crafted a mixed methods study to explore the mechanisms underlying the development of identity complexity and life quality in individuals with developmental disabilities (IWDD) using qualitative interviews and hierarchical classes (HICLAS) analysis. Designs incorporating qualitative methods are well poised to capture data related to the experience of disability as in-depth interviews place foci on the individual's perceptions of their experiences based on the social contexts in which they have them (Charmaz, 1994). Hence, I utilized in-depth interviews in order to capture each person's voice and perspective.

Research exists using qualitative methods to examine the experiences of those living with physical disabilities (Jones, Marshall, Lawthom, & Read, 2013) and there is now emerging literature examining phenomenological perspectives of individuals with cognitive impairments (Marshall, Nixon, Nepveux, Vo, Wilson, Flicker et.al., 2012), however, qualitative techniques have been rarely utilized for individuals with both physical and cognitive disabilities that may impact both expressive and receptive language respectively and in combination. I thought this to be an important gap in the literature and that the advent of new communication strategies may ameliorate the difficulties which inhibit researchers from using these techniques. I looked forward to the challenge of incorporating assistive technology (such as voice output devices) and other alternative communication strategies (communication boards, icons/symbols) as communication bridges which could allow individuals who are non-verbal to participate in this project. Unfortunately I could not include those I believed would not be able to



comprehend the questions asked or whose communication systems I was unable to navigate either independently or with a familiar other who could assist during the interviews.

The qualitative interviews were triangulated with hierarchical classes (HICLAS) analysis. HICLAS analysis is a method that examines the various roles an individual adopts and the attributes related to those roles. This method has been used to examine the hierarchical structures of identity in various populations including: those with psychosis, gender issues, adolescents, and individuals with developmental disabilities. HICLAS analytical strategy is comprised of a sequence of short, structured surveys that guide the participants in identifying relationships and roles that are important in their lives. The information is entered into an algorithm that collapses the resulting identities into clusters based on co-occurrences with the self-ascribed features attributed to them by the participant. A structural map is created which visually depicts the interrelationships and hierarchy of those various roles in relation to the features (descriptors) they share. For example, the role of ‘myself as an artist’ may include features of ‘artistic,’ ‘creative,’ ‘productive’ and these feature may overlap with the role of ‘myself as one who has disability’.

Individuals with schizophrenia (Robey, Cohen, & Gara, 1989), delusional psychosis (Dean, Elvegag, Storms, & Diaz-Asper, 2009), and spastic quadriplegia secondary to cerebral palsy (CP) (Clarkson & Robey, 2000; Robey, 1997; 2008), have been studied using this conceptual framework and method of analysis. In addition, investigations into sexual, racial and gender identities (Stirrat, Meyer, Ouellette, & Gara, 2008) and adolescent identities (Elbogen, Carlo, & Spaulding, 2001) have also utilized

the HICLAS analysis method. Literature exists supporting the concurrent and discriminant validity of this methodology (Friedman & Haaga, 2007).

In combination, the qualitative interview and the HICLAS analysis triangulate the data obtained. An unforeseen benefit of this mixed approach was that the sequential series of interviews afforded the participant and me the opportunity to develop rapport over the course of the 5-7 weeks during which the total series of interviews were conducted. In addition, the short answer nature of the HICLAS analysis process was easier for some of the participants to respond to; in essence it mirrored their more customary manner of interpersonal communication.

To summarize the underlying rationale for combining these two strategies, qualitative techniques capture nuance and meaning related to intangible and self-ascribed constructs such as identity complexity and life quality. Unique experiences call for an analytical design that allows participants to fully express meanings they attribute to their experiences (Charmaz, 2011). Thematic analysis of data provides an informative means of interpreting and analyzing the information obtained from the qualitative interviews (Floersch, Longhofer, Kranke, & Townsend, 2010). Floersch, et al. (2010) advocate the use of a ‘concatenated’ analytical technique. This strategy integrates thematic analysis, grounded theory and narrative techniques into a hybrid approach which may have merit for establishing a “plausible and robust account of the object of study” (p. 421).

HICLAS analysis is ideally suited for an exploration of the multiplicity of identities that individuals hold (Stirratt et al., 2008) and indicates the self-ascribed importance that each identity has for the individual creating a hierarchy of their self-perceptions. In order to obtain a multidimensional understanding of phenomenological

experiences in relation to the self-ascribed importance of various roles and relationships IWDD may hold, the combination of HICLAS analysis and in-depth interviews provided a synergistic pairing. This chapter will outline in detail the design of my research, identify justifications for its methods, and describe additional methods of triangulation.

### **Research Design Overview**

I obtained approvals from the Institutional Review Board for the organization that provides residential and day program services for the participants, as well as from Rutgers University's Institutional Review Board. In addition, approval was obtained from the New Jersey Department of Human Services Division of Developmental Disabilities' (DDD) Quality Assurance officer and signed off by Dawn Apgar, the Deputy Commissioner for DDD. Final DDD approval was received in December 2012. IRB renewals were updated yearly (from September 2012 through the present).

Interviews were conducted in a private office space arranged for the participant's convenience either in an Adult Day Program location, in his/her private bedroom, or in my private office. For the community based participant living with her family of origin, the interviews were conducted in her home at her request. Qualitative in-depth interviews and HICLAS analysis were used with each participant. The qualitative interviews were alternated with the HICLAS analysis process within each subsample (i.e. half of each group was interviewed before completing the HICLAS surveys; the other half interviewed following the HICLAS surveys) to control for effects of instrumentation. HICLAS surveys range from 45 minutes to 60 minutes, and involve obtaining free response self-descriptive data over the course of several sessions (see HICLAS

methodology section). The qualitative interview took approximately 60-90 minutes to complete (see Qualitative Interview section).

### **Research Sample**

A purposive, convenience sample was selected from participants who are affiliated with the umbrella Medical and Educational Center (MEC), either as residents of the agency's hospital, group homes, Adult Day Program (ADP) or participants in their facilitated arts program. Purposeful sampling allows for selection from a population that has familiarity with the material an investigator is interested in studying (Denzin & Lincoln, 2011). Participant recruitment consisted of verbal announcements at staff meetings, information and recruitment visits to the ADP and direct outreach by phone and email to group homes, the Arts Access Program and residential programming staff for referrals. Participants were then approached and recruited in person at the various venues. I did not recruit participants with whom I had previous direct clinical contact in order to avoid becoming overly immersed in their culture (Shenton, 2004).

A data summary sheet was completed with participants that included demographic, medical and living situation information. Half the participants in each cell were first interviewed using the qualitative interview guide. Interviews were audio-recorded and transcribed by me with no outside assistance in order to promote my familiarity with the data. Following the qualitative interview session, participants completed the HICLAS series. This sequence was then reversed for the other half of the individuals in each cell, i.e. HICLAS series first, then the qualitative in-depth interview. (see Table 1 for participant characteristics).

Table 1. Participant Characteristics n=20

Variable	Frequency	Percent
Gender		
Male	13	65%
Female	7	35%
Race/Ethnicity		
Caucasian	11	55%
African American	5	25%
Hispanic	4	20%
Medical diagnosis		
Cerebral palsy	13	65%
Spina Bifida	2	10%
Lesch Nyhan Disease	5	25%
Psychiatric diagnosis		
ODD	1	5%
Depression	5	25%
Anxiety	2	10%
	<u>Mean</u>	<u>Range</u>
Age	36.00	20-54
Verbal IQ (WAIS)	72.08	58-97

Attempts were made to get similar cell sample sizes based on residential living situations i.e. residents of a specialized hospital, those who reside in community based group homes, with their family of origin (FOO) or assisted/supportive apartment dwellings (see Table 2).

Table 2. Participant Living Situation.

	Arts Access Participants	Non Arts Access Participants	<u>Total</u>
Group Home Residents	5	1	6
Institutional Residents	5	6	11
Family of Origin Supervised apt	1 2	0 0	3
Total	13	7	20

While not a primary focus of this research project, the rationale behind these cell groups is to control for any differences in the manner in which individuals may experience art-making and subsequent impacts on identity based on residential setting. Inclusion criteria included the need to have sufficient receptive language capacity to comprehend, and sufficient expressive language ability to be able to respond to the interview questions. Assistive communication devices, communication boards and communication partners (i.e. adult service staff) were utilized to afford individuals who are able to receptively understand questions the ability to express themselves when they were unable to in an ordinary verbal manner.

### **HICLAS Methodology**

Administration of the HICLAS series is a multi-stepped process: First, the participants are asked to create an inventory of various identities associated with social roles inherent in relationships with others and in various social situations. Roles are comprised of relational, avocational and spiritual domains. For example, such personas may consist of: ‘myself as a daughter’, ‘actor’, or ‘Protestant’ respectively.

Next, they are asked to rate each identity on a scale from one to five indicating importance of that identity within their self-concept. A score of one indicates little to no

importance and a score of five indicates extreme importance. Then, they are asked to rate each identity with regards to their valence i.e. whether considered a positive or negative identity. The identities are then streamlined down to twelve to sixteen as scored highest by the individuals in relation to their perceived degree of importance to their self-concept. At this stage in the process, the participants are asked to characterize each of their identities with a set of features describing themselves when enacting that identity, thus creating an individualized vocabulary of fifty items. These features are statements such as playful, frustrated, happy, etc.

In the final phase they are asked to rate each set of identities in association with the various features. Checklist forms with each of the identities as headings are created with the list of the various features underneath each identity heading. The participants identify whether that feature is present when thinking of themselves enacting that particular identity and then rated on a two point scale: 0 (not present), or 1 (present most of the time). Data are organized into an identity X features matrix consisting of twelve to sixteen selves by approximately fifty features and subsequently analyzed using the computer-based 'HICLAS' algorithm.

**Statistics.** I used version 1.1 of HICLAS to model the implicit interrelationships among the identities (De Boeck & Rosenberg, 1988). These identities are hierarchically organized based on the commonalities of shared features as articulated by the participants to describe themselves when enacting each identity. For example, the roles of 'myself as an artist' and 'myself as one with disability' may include shared features of 'special gift', 'accomplished,' and 'proud'.

HICLAS operates via an iterative process producing levels of differentiation of data to identify various identity clusters and their corresponding feature clusters. The algorithm allows the researcher to construct structural representations at various “Ranks” or levels of differentiation. The higher the Rank, the more finely differentiated are the hierarchical relationships between and among the various identities and associated feature clusters. The analysis employed HICLAS results at a Rank 3 solution in order to be consistent with previous studies’ methodology. A Rank 3 solution distributes the identity clusters and the feature clusters into three hierarchical levels and has been posited in the literature to preserve the clearest interpretability of the data (Robey, 1997; 2008).

### **Qualitative Interviews:**

In order to further explore the research questions, I conducted in-depth interviews. In-depth interviews are highly useful for qualitative research exploring various social justice issues (Charmaz, 2011), in part because they provide investigators with access to others’ experiences through narration of personal stories from which investigators can then develop insights (Patton, 2002). I crafted an interview guide following a comprehensive review of the research on disability and identity. In addition, I addressed areas covered in the HICLAS questionnaires with regards to social roles, activities, family and cultural affiliations in order to gain deeper understanding of the meaning those areas may hold for participants.

**Research questions.** The overarching goal of this study is to better understand the antecedents of identity complexity. More specifically, I am seeking to understand how various personal characteristics, roles, activities, and relationships impact the development of IWDD’s self-concepts and self-appraisals. Further, the impact that



involvement in a facilitated arts program i.e. Arts Access may have on the development and complexity of IWDD self-concept is an additional component of this study. Hence, this study seeks to answer the following research questions:

- 1) How do IWDD make meaning of their identity?
- 2) How does the disability identity manifest itself within their multiplicity of identities?
- 3) What types of experiences enhance life quality and self-perceptions for IWDD?
- 4) What is the impact of participation in a facilitated arts program on identity complexity?

These questions frame this study; I seek to capture the meaning disability holds for the participants and to explore how exposure to various social contextual environments may impact the evolution of self-conceptions.

**Developing the interview guide.** I constructed open ended questions with the intent of eliciting personal accounts of participants' experiences and self-concepts. I avoided leading questions that may have some sort of judgmental connotation attached (see appendix 1). I then followed up with probes following the direction of the participant.

Qualitative strategies instruct that data guide the research and as a result, the interview guide was altered during the course of the project to more accurately reflect the experiences of the participants. For example, the question of 'could you please describe how your day to day life has been affected by having your disability?' was perceived to be incongruent with the participants' experiences as they had no life experience of being

nondisabled. Thus, the question was altered to ‘how do you perceive your life might be different if you did not have your disabilities?’

**Data collection.** I conducted all of the interviews either in my private office, the participant’s private bedroom, a private office in the Adult Day Program or, as in one case, home of the family of origin. Participants, if able, would arrive independently to the interview location. In the event that they were unable to travel independently, I would pick them up and transport them (as in the case of participants with LND who were unable to navigate their environment independently due to safe guarding equipment). I attempted to split the participants into two equivalent groups in sequencing the interviews. As previously described, each group either initially completed the series of HICLAS surveys or the in-depth interview first. If the HICLAS series was first, this entailed several shorter meetings covering the next five to seven sequential weeks, each meeting taking approximately thirty to sixty minutes in duration. The longer qualitative interview (at the last session) would take approximately forty-five to ninety minutes to complete. This scenario was reversed for the other half of the sample with the qualitative interview administered at the first session followed in successive weeks by the HICLAS sequence.

As a function of many years’ experience working with verbal and nonverbal IWDD, I have gained specific knowledge enabling interpretation and translation of various communication modalities that were employed by some participants. However, due to expressive language impairments of many in the sample related to their physical disabilities, some audio-recordings had to be listened to several times in order to get as much of the spoken text as possible. This afforded me additional opportunity to become

increasingly grounded in the data. The qualitative interview was the only portion of the sessions that was audio-recorded. The first few transcriptions of the audio-recordings were sent to the Dissertation Chair for review in order to ensure the integrity of the process with regards to a) capturing the experiences sought and b) that the interview technique employed was unobtrusive and non-coercive. This also allowed discussion of the beginnings of a coding scheme.

**Consent/assent/withdrawal.** Legal guardian consent was obtained in advance when necessary and in all cases, informed consent or assent forms were completed with the participant directly depending on whether the participant was deemed competent or assigned a legal guardian. Most guardians resided out of town which necessitated that the consent forms be mailed and reviewed in a phone conversation. In addition, all participants/guardians needed to provide written assent/consent in order to be audio recorded during the qualitative component of the research project.

The process of obtaining consent became, in some cases, a research conundrum that had to be carefully negotiated with adult guardians who became the gate keepers for those deemed legally unable to consent. Two guardians refused to provide consent when their adult children indicated a desire to participate. In one case, the guardian believed that her child would not be able to comprehend the interview questions sufficiently to provide appropriate responses. In the other case, the guardian wanted to shield her child from any stress that may be elicited from the interview questions as that person (i.e. the potential participant) had recently experienced loss. In obtaining informed consent/assent of the participants, language comprehension and expressive language issues needed to be considered along with complicated medical treatment regimes. I reviewed the forms in

detail with the participants and provided them with a copy of the information and appropriate contact numbers of myself as researcher and my advisors as well as IRB contact information in case of follow up questions.

Consent was viewed as a continuous process throughout the duration of the project and I made sure to check in at every session with each participant regarding their desire to continue with the project. Further I needed to pay close attention to body language and other nonverbal cues and reiterate that the person may withdraw without ill effects. Persons with cognitive impairment are prone to acquiesce and due to social desirability factors may continue with the project in order to comply with the researchers' desires even when they would rather not continue (McDonald & Raymaker, 2013).

A total of two participants ended up withdrawing before completing the interview sequences. Both stated that they felt that 'it [the research experience] was not for them' and I avoided pressing for more detail as that risked coercing them back into the study. I believe a loss of two participants is an acceptable attrition rate out of a total pool of twenty-two participants. Careful description of the research project had to be provided in basic language. I used short sentences, continually checked in with the participants for their understanding of the project's parameters, and assessed the ongoing interest the participant had in continuing with the interview process at each interview session in the sequence.

**Data analysis strategy.** Charmaz (1994, 2002) identifies a number of activities associated with the generation of grounded theories:

- simultaneous collection and analysis of data

- creation of analytic codes and categories developed from data and not by pre-existing conceptualizations (theoretical sensitivity)
- discovery of basic social processes in the data
- inductive construction of abstract categories
- theoretical sampling to refine categories
- writing analytical memos as the stage between coding and writing
- the integration of categories into a theoretical framework.

I incorporated these activities within the concatenation approach described by Floersch, et.al. (2010). The analysis involved a sequential process in organizing and analyzing the data obtained from interviews. Following each qualitative interview, I wrote a reflective memo which encapsulated my sense of the process and flow of the interview as well as any specific themes that emerged.

First, the audio- recordings were transcribed (along with the reflective memo) and uploaded into ATLAS.ti software. Once uploaded into ATLAS.ti, I assigned open codes to the data by placing a preliminary label on them. Preliminary codes were derived from three main categories:

1. Theoretical categories; labels reflecting the various themes emanating from theory on identity formation using the social model and interpersonal theories to reflect the development of social relationships
2. Inductive categories: categories that emerged from the data such as ‘gaining understanding’
3. Emic categories: as identified by the participants using their own verbiage such as ‘nothing stops me’

In the second stage of analysis, I employed axial coding to assign individual codes to a thematic category. Themes were identified through an iterative process in which I alternated between asking questions about the data and returning to the data to verify and compare prior understandings with emerging concepts. Constant comparison is a strategy for analyzing text associated with grounded theory; its purpose is to make sense of the qualitative material and ultimately identify recurring foci (Charmaz, 2011). This method has the advantage of being unobtrusive and is a relatively expedient mechanism to analyze a significant amount of text (Trochim & Donnelly, 2008). A coding matrix was constructed (see figure 2) to provide a context for thinking about the systematic interrelationships and patterns among the data. The resulting matrix visually portrayed the connections among the various emergent themes and provided a roadmap for conceptualizing an overriding rationale of how self-concepts evolve and impact life quality.

In the final stage, interpretations were placed on those thematic categories to establish cohesive understanding of the phenomenological experience of the participants. More explicitly, grounded theory technique guided the utilization of thematic categories in developing a conceptual framework for understanding participants' self-concepts and life quality. I developed a conceptual model to reflect the interrelated processes engaged in by participants as they strive to achieve life quality i.e. sense of interpersonal acceptance/integration within their social contexts.

While hoping to achieve theoretical sampling and a robust sample, I was limited by the availability of my participant pool. I did receive many suggestions by staff for appropriate participants, but needed to be sensitive to the potential of coercion due to

social desirability tendencies of the population. Hence, if a participant did not actively seek to be involved after the initial presentation, I would not follow up further. Over time my sensitivity to the receptive language issues improved, i.e. I needed to break down information into simple language and use short sentences. In addition, I became immersed in the environmental culture through prolonged exposure which increased potential participants' familiarity and comfort with me. As a result, I was able to recruit additional participants who actually approached me and requested involvement. According to Charmaz (2011), theoretical sampling occurs after the initial data gathering collection and analysis. The addition of two participants occurred several weeks following the sorting and coding of previous interviews and indicated no further emergent categories. This observation implied that saturation (for this sample) was achieved.

My experience in collecting qualitative data from individuals with expressive and receptive language difficulties differed from interviewing more traditional populations and impacted the overall analysis process. Qualitative inquiry posits that there should be narrative discourse to code and analyze. However, my interviews consisted of interactive dialogue and short sentences. My participants generally did not produce long paragraphs of narrative discourse for analysis due to their physical and cognitive impairments. I needed to use probes, repetitions, reframing and reflection; in effect, several lines of dialogue ended up encapsulated in any particular substantive code and often included interviewer dialogue as well as the participants' in order to convey meaning.

### **Establishing Trustworthiness**

Due to the subjective nature of qualitative research, it is incumbent upon the researcher to apply several strategies to ensure that the information obtained truly captures the voice of the population of interest (Lietz, Langer, & Furman, 2006). The term ‘rigor’ in qualitative research is analogous to achieving ‘validity’ in quantitative circles. According to Lietz, et. al. (2006), rigor suggests that the research has been subjected to efforts that increase confidence that findings are representative of the meanings presented by our participants. These efforts should place awareness on how we interpret data in order to minimize reactivity, bias and in essence place priority on the voices of the participants. This section will detail the various measures I utilized to authenticate the voices of my participants.

**Reflexivity.** In order to enhance rigor, I engaged in a process coined ‘reflexivity.’ All researchers enter a project with their own preconceived ideas on the phenomenon they seek to study. I needed clarity on what my own preconceptions were related to potential antecedents of identity complexity and life quality in IWDD. In effect, my research questions and my own perceptions evolved as I reflected on the voices of my participants as they described their experiences living with multiple disabilities and how they perceived social and environmental interactions through their unique lenses. This process was dynamic and ebbed and flowed throughout the data gathering process and analysis.

I began this project with the underlying assumption that all people have a right to be treated with dignity and respect and further that IWDD’s voices were not being adequately heard. Marginalized populations typically are overlooked and underrepresented in various social/community initiatives (Charmaz, 2008). As a social



worker, it is part of my professional mission to serve as a voice for those who are unable to self-advocate. I was aware of the potential for communication difficulties due to receptive and expressive language impairments emanating from cognitive and physical disabilities respectively and in combination. Despite these research conundrums (Wilkenfeld, 2014) I felt it was imperative to acquire additional knowledge and skills to be able to adequately negotiate the interview process. This initiative was further underscored as I progressed through the interview process and was confronted with many of these communication dilemmas in attempting to obtain their personal ‘voice’.

Further, it is important to note that I do not have developmental disabilities and while I do have acquired chronic illnesses, the nature and impact on my life is quite different than that which my participants experience. Participants all have lifelong, highly visible disabilities. I engaged in this reflexive process internally (i.e. with much self-reflection and reconceptualization) and externally (through meetings with my fellow clinical social workers in the practice setting and ongoing dialogue with my dissertation chair) (these will be discussed further in ‘external auditors’ section).

**Positionality statement.** Phenomenological perspectives explicate the “lived experiences” of individuals with disabilities. This endeavor involves understanding aspects of the person’s various social contexts that may impact their lives and sense of self from their point of view. Social workers have unique strengths in utilizing qualitative methods to explore these phenomena (McCoyd & Shdaimah, 2007; Pieper & Tyson, 1999) although some propose a contrary view and do not believe the social worker/interviewer connection is quite as strong (Padgett, 1998) . Despite this debate, it is my contention that due to the profession’s emphasis on social interactions and

engagement, communication with marginalized populations is enhanced by trained and experienced clinicians familiar with the specific challenges this population experiences. I have worked with this population as a clinical hospital and school social worker for the past seven years, and subsequently have a deep, nuanced understanding of this specific population (i.e. IWDD). In addition I have familiarity with their various communication strategies/behaviors and so am uniquely positioned to conduct this research project.

**Memos and field notes.** One of the strengths of grounded theory approaches is the ability to follow where data lead. The flexibility of this approach necessitates a scrupulous documentation of the signposts that guide the researcher to the ultimate destination. Hence, memos and field notes were crucial components, like the color coded signs on hiking trails which indicate to fellow travelers how you navigated that particular terrain. For example, theory and preexisting policy initiatives indicated the need for breaking down various barriers for IWDD to be able to integrate successfully into general society. Focus had been placed on physical/environmental barriers that needed to be overcome for IWDD to be fully immersed into various social contexts. I approached this project with certain preconceived assumptions regarding the importance of environmental barriers and functional limitations in preventing IWDD from fully engaging in preferred activities. Upon listening to the participants' voices, it appears as though the barriers were much more complex than this and of a more abstract and interpersonal nature. IWDD seemed to understand that there existed a hierarchy in social relationships that might not be able to be overcome by merely physically placing the individual within certain social contexts. This observation has led me in a different direction to focus on

stigma and societal objectives for integrated vs intentional communities (enhancing the disability identity and strengthening allegiance to disability communities).

I wrote memos following every in-depth interview prior to typing and uploading the transcription into ATLAS.ti. This activity facilitated my grounding in the data as it was unfolding. I examined my sense of how theory interacted with the information obtained from the interview and reflected on emergent themes or categories that seemed to account for the unfolding processes. This was described by Charmaz (1990) as a continually evolving process that really has no end since the memos become increasingly conceptual as the analysis progresses until the grounded theory becomes fully articulated.

**Prolonged engagement.** As indicated in my positionality statement, I am a clinician working within the umbrella organization with a younger population for the past seven years. As such I have a familiarity with the overall population, their communication strategies and the social elements which impact their general life experience. I am known to most of the participants as a social worker in the facility which may have provided them with a level of trust and comfort as many have felt stigmatized and alienated by unknown others (members of the general population). I was able to navigate certain environmental ‘gate keepers’ with greater ease than an outside researcher as I had the support of the administration and the organization research director in conducting my project. Knowing staff at the Adult Day Program and at Arts Access provided me with the assistance of trusted familiar others to allow access and introduce me to participants I had not met before. Overall, I believe that my many years of work within the parent organization provided me with a particularly keen understanding of the culture and communication styles of the population which facilitated

my ability to develop rapport and relationship with participants. In addition, by engaging in a series of shorter interviews over a longer time frame (when doing the HICLAS interviews), I was able to further strengthen relationship and trust resulting in further freedom of self-disclosure of the participants.

**External auditors (and peer scrutiny).** My dissertation chair served as one external auditor. In my enthusiastic naiveté, I was quick to come to conclusions and decisions with regards to the interpretations I was placing on the data. My dissertation chair challenged conclusions and redirected me back to the literature and alternate interpretations of data.

My director of Social Services and the director of Psychological Services also served as external auditors. Both have been employed in their respective capacities for the past ten years and have acute awareness of the various issues my participants are confronted with from both clinical and administrative points of view. I provided them each with some background information surrounding my topic and methodology choices. I then provided a guided tour of my data collection process and analytical strategy which ultimately resulted in the generation of theory. Aside from corroborating my findings, my social work director created a scenario from his own personal experiences and applied it to the theoretical model that I generated from the data. We discussed how various interventions and formal quantitative tests could be applied to the various constructs within the model. This process lent credibility to the model and also helped to clarify for me the various constructs and applications for this theory in more generalized contexts. Both external auditors felt the data collection and analysis strategies made

sense and were impressed with the amount of data obtained and the overall integration of the findings.

In addition, I used my work colleagues as additional sounding boards; I presented my thoughts to them in casual settings to elicit their superficial, immediate responses to the emerging themes. Corroboration or refutation by these individuals who were working closely with the population provided me with further insight to either confirm or reevaluate my findings.

**Member checking.** Member checking refers to obtaining systematic checks and feedback from the population being studied (Charmaz, 2011). Following the initial analysis, I met with several of the participants to share with them the thematic categories and my perception of the interactions between those categories in order to establish confirmability. These participants felt the themes and ultimate conclusion fit well with their experiences. Ultimately, those conclusions are related to acceptance/integration into the social community at large, a circumstance that all participants indicated was of importance in gaining a sense of well-being.

**Comparison to HICLAS themes.** I compared themes derived from the HICLAS analyses to the themes emerging from the qualitative interviews as an additional check for credibility and reinforcement (or contradiction) of the findings. Triangulating qualitative interviews with a mixed method approach may counteract any limitations in the methods and may exploit their individual benefits (Shenton, 2004). In engaging in social justice research, mixed methods research affords the investigator an opportunity to gain a more nuanced understanding of the research problem (Charmaz, 2011). An unforeseen additional advantage of the HICLAS method was related to the inherent

sequential process which involves a series of shorter interviews over the course of several weeks. This provided us (i.e. myself and the participant) an opportunity to develop rapport and relationship which facilitated the participants' freedom in expressing emotionally laced, rich information related to their experiences at a later stage in the interview process (see prolonged engagement).

## **Chapter 4. Recognition**

### **Introduction to the Findings**

Here I will discuss findings which emerged from interviews conducted with the twenty participants in my research sample. In order to organize the numerous codes into categories, I created a coding matrix (see Figure 2). The matrix illustrates the coding strategy and emerging analytic process. This process serves as the foundation for generating theory on the interactive mechanisms underlying the development of self-concept and life quality for individuals with developmental disability (IWDD). As previously mentioned (in Chapter 3, Methods), the first step in data analysis in grounded theory is to assign preliminary open codes to the text thereby creating initial categories of information. In the second stage, I employed axial coding to assign open codes to thematic categories through an iterative process which involved constant comparison to identify recurring foci (Charmaz, 2011). The integration of categories within a theoretical framework represents the final stage of this data analysis strategy resulting in generation of grounded theory.

As illustrated in the matrix, I theorize that IWDD engage in three general processes as they develop complex self-concept and these processes happen at three degrees of separation from self (self, known others, unknown others) : Recognition, Response and Reconciliation, respectively. The three processes act within cognitive, emotional and behavioral domains and ultimately inspire ‘Desire for Acceptance/Integration’ at micro (i.e. interpersonal interactions) and meso (i.e. community interactions) levels. These interactions yield implications at the macro level (societal policy initiatives, theory). I have labeled the three processes: Recognition,

Table 3. Coding Matrix

DEGREE OF SEPARATION /LEVEL OF RESPONSE	RECOGNITION	RESPONSE	RECONCILIATION
Self	Task: Complexity of identities vs sparseness	Task: Resiliency vs Pain and Despair	Task: Acceptance vs rejection of negatively perceived identities
Known Others (Family/Friends/Caregivers)	Task: Impact on self-concepts	Task: Belonging vs Rejection	Task: Acceptance by known others/ Intimacy vs Isolation
Unknown Others (Strangers)	Task: Impact on self-concepts	Task: Inclusion vs Ostracism	Task: Acceptance by unknown others/ Community integration vs Isolation

Response and Reconciliation to further delineate the individualized characteristics defining these categories which operate in cognitive (thinking), emotional (feeling) and behavioral (action) domains, respectively. Self-concept (the result of cognitive self-appraisals in each of these categories) is impacted by, as well as affects, the resolution of tasks at intrapersonal and extra-personal levels across emotional and behavioral domains.

Each process will have its own findings chapter. Open coding will be presented in table format at the beginning of each subcategory (or axial codes) within each section along with some example quotes. Emphasis will be placed on axial codes i.e. table titles. Finally, I will present the interconnections of these categories in a theoretical framework in the final chapter. In summary, the open codes are raised to increasingly abstract and finally a theoretical level. Further reinforcement or refutation of the findings is provided by analysis of the emergent themes from the HICLAS analytical process.



As mentioned in the Methods section, some participants have communication deficits, and as a consequence, an interactive discussion ensued. I needed to flesh out meaning which entailed some exploration and reflection. As a result, rather than presenting a succinct quote to justify a theme, a dialogue is presented so that the particular person's voice is able to be represented in the data.

**Core category: 'Desire for Acceptance/Integration'.** The core category, 'Desire for Acceptance/Integration' reflects an overriding desire of participants for societal integration and acceptance by known and unknown others. This core category emerged as pervasive throughout the interviews. This desire for acceptance/integration underscores the reflexive interactions of processes impacting self-concept and a sense of well-being/life quality for IWDD. Participants are aware of their 'differentness' from 'normal' society (groups of individuals without disability) and are aware of others' perceptions as Grace, Shannah and Tanya relate their experiences of being in the community. Grace states "I wish people would see, you know, different people for what they are. They're just different." Shannah types out: "O-K ... A-Y...OKAY... D-DIFFERENT...OKAY TO BE DIFFERENT" and Tanya reflects "When I go to the mall, they look at me weird so I say 'hello' to them because they don't know that I speak."

Elements from symbolic interactionism seem appropriate in framing the experiences described by participants in relation to how they believe they are perceived by others and subsequently how they perceive themselves. According to Blumer (Blumer, 1969, p. 2)

Human beings act towards things on the basis of the meanings that these things have for them. The meaning of such things is derived from, and arises out of, the

social interaction that one has with one's fellows. These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the thing he encounters.

The previous participants' quotes illustrate that IWDD engage in this interpretive process as described by Blumer and are aware that others in the community are reacting to them based on preconceived stereotypes.

In summary, IWDD who participated in this project have an acute awareness of 'being different' and having negative attributes assigned to them based on stereotyping processes in community interactions. There is an inherent need to be accepted in group interactions (Walton, Cohen, Cwir, & Spencer, 2012) and this overriding desire for 'acceptance/integration' becomes the core category in this project. The next subchapters will explore the three reflexive processes which impact, and are impacted by, this overriding need for acceptance and integration.

Recognition is one of three overarching thematic categories and represents the cognitive self-appraisals of IWDD in this project. Cognitive self-appraisals are a component of self-concept related to how IWDD make meaning of who they are and their place in the world. To review, one's self-concept is partly comprised of a collection of multiple, context dependent identities. Identity complexity is defined by maintaining multiple identities which are described by: (a) personal characteristics and (b) social roles which are associated with features (the qualities and characteristics of the roles as an individual enacts them).

The combination of identities and associated features are referred to here as cognitive self-appraisals and are depicted under the thematic category of: Recognition.

For example: a salient identity for these participants is the ‘disability identity.’ This ‘identity’ is associated with both positive and negative features for all of the participants in this study. It factors into all other aspects of their lives and is associated with the other identities within their self-concept. As such, the disability identity is positioned within the person’s self-concept and becomes its own subcategory within this domain.

These self-appraisals vary depending on whether one is thinking about him/herself in relation to known or unknown others. Here I will be using ‘known others’ to refer to friends, family and staff who are well known to the IWDD; ‘unknown others’ will be used to refer to people with whom there is social distance- people encountered in stores, on the street, and in other social situations.

Self-Recognition becomes the first subcategory of this theme and refers to the various meaning making strategies IWDD in this study use to achieve understanding of who they are and their place in the world. These rationalizations are inherent (i.e. internally derived) to the individual. In contrast, the other subcategories describing their reactions and meaning making processes are relational and vary based on whether thinking about ‘known’ i.e. familiar others (second subcategory) vs. ‘unknown’ strangers in the community (third subcategory). These subcategories relate to the task of assessing ‘how others see me.’

### **Self-Recognition**

Self-Recognition (an internally derived phenomenon) is defined by four axial codes (table titles). First, participants engage in a process of *creating rationales* to understand and explain their reactions to having disability. Second, they also seem to intuitively perceive the need to assume a more valued social status in relation to peers

which I have termed *hierarchy*. Third, they engage in a dynamic process of *gaining understanding* over time and experiences. Fourth, in addition to these processes participants acknowledge their ‘disability identity’ as a salient identity within their self-concept.

### Created Rationales

OPEN CODE	Example Statement
Why Me?	I always say ‘why me, why not anybody else’.
Rationalizations: staying positive/ it could be worse/ Gaining advantages	Think of the positive things that you have and (indecipherable) put your mind to it and keep it moving ...  I loved it and I never heard of you know wheelchair ballet dancing you know and that was different.
Spirituality: for a purpose	I believe that god...created people... and certain children...different situations...for a purpose...(and I’m not complaining about it, I have no choice)

**Why me?** IWDD engaged in a process of questioning and rationalizing the reasons for having their condition in order to make meaning of having disability in their lives. As one individual stated “you try to make the best of it.” Due to the developmental nature of their disabilities, the IWDD in this sample have known no other life experience other than being ‘disabled.’ This concept may contrast with others who may have acquired their disabilities later in life and have experienced life without having any functional limitations.

IWDD in this sample only become aware of their differentness when informed by others i.e. when they develop more social consciousness and understand that they are ‘different’ and have functional limitations not found in the majority of people in society.

As individuals mature and gain awareness of how they differ from typical individuals (i.e. those without disabilities), they strive to develop a rationale for why they have their disabilities. Further reflections articulating this theme include: “Sometimes...I wonder why I’m this way” and “Why did this happen to me... I have a purpose in this life.”

Jaleel is a young man with cerebral palsy (CP). He speculates here on the reason why he has his condition:

There’s a reason for me to have it I don’t know what it is but I will find out...I could see that my disability at times ...could be a negative but at more positive than negative because you know...if I didn’t have this maybe I wouldn’t be the [same] person...

Jaleel is acknowledging his awareness that his disabilities can be both positive and negative in his life. He appears to understand that having disability is salient to impacting who he is as a person and that not having disability may significantly affect this sense of self.

**Rationalizations: staying positive.** Another created rationale incorporated under rationalizations is ‘staying positive,’ i.e. maintaining a positive outlook. This is a commonly used coping strategy and is the basis for solution focused therapies and is also used in strength perspective outlooks. Forty one quotes were coded with this label. As Allan, who has spina bifida, reflects:

I always um find a way to be able to look at the bright side of a situation uh rather to look at all the negatives of a situation... stay positive you know and hoping always for a better day and I know that it will come, they have come.

Sofia, an outspoken young woman with spina bifida also chooses to focus on the positive aspects of her life, she discloses “I try to focus on the good things instead of the bad things that are bothering me and I try to stay focused on what’s good in my life instead of the negative.” Grace is a young woman with CP who enjoys mentoring others. She reflects that there is a positive impact of having disability on impacting others “...they [people] admire the fact that I can have this disability and be so positive.” The previous quotes indicate that participants utilize positive thinking i.e. focusing on the positives including the positive impact that [their] having disability might have on others and maintaining a hopeful outlook as strategies to cope with having disabilities.

Participants seem to recognize that by assuming a positive outlook, they feel better about their circumstances rather than focusing on the negatives related to their disabilities. Carl is an articulate man with CP in his 40’s who resides in a group home. He reflects on how his life might be different if he did not have his disability; he also chooses to focus on the positives as he explains “I could see it as a plus now I could see it as a negative at times too but I don’t dwell I don’t sit there I don’t have time to sit there and dwell.”

**Rationalizations: it could be worse.** The next two reflections indicate that some credit their disability with preventing them from engaging in self-destructive behaviors. They are aware that siblings and other family members engage in antisocial behaviors, have legal difficulties, are unwed parents, struggle with poverty, and/or have nefarious social associates. Shannah is a young woman with CP who uses a voice communication device (i.e. capital letters are entire words written and artificially voiced by her communication device, and the letters with hyphens are individual letters spelling out

words on her device). The following dialogue indicates how she credits having disability with keeping her safe.

Bonnie: Are there any positive aspects of having a disability?

Shannah: IT MADE ME LIVE S-A-F-E SAFE

Bonnie: Having a disability made you safe? Can you explain to me what you mean by that?

Shannah: I AM W-I-L-D

Bonnie: You're wild... What do you think you would be doing with your wild spirit?

Shannah: WILD D-R-U-G

Allan, a man with spina bifida, echoes this reflection regarding his sense that having disability actually prevented him from engaging in self-destructive behaviors:

I feel like it helped me mature in a lot of ways and...also growing up from where I grew up, I feel like it also put a damper on me getting in trouble you know and and following certain things.

Others acknowledge that "it could be worse" as another way of creating rationalizations for why they have disability. Participants reframe their experiences in a positively oriented direction when they rationalize that 'it could be worse.' This mirrors the finding above in '*Why me?*' and in the rationale of '*being positive.*' This principle is illustrated by the following quotes. First Allan reflects on others who are worse off than he is:

Someone is out there right now who is homeless. There's someone out there you know that's trying to get food there's someone...out there that's worse off than

me you know so who am I to sit here and complain of what I'm going through right now you know?

Henry, an outgoing, verbose man with CP expresses some strong feelings about those who focus on feeling sorry for themselves:

I do have a message for the people that do get down on themselves for any of this [having disability] mean it could be much worse...I guess that for some people there will always be you know 'woe is me' again I could say 'it could be much worse' you could not be here at all.

As indicated in the above reflections, these individuals contemplate how life could be worse, understanding that others (who are non-disabled) have life struggles. Henry recognizes that some people allow themselves to be consumed by depressing circumstances in their lives. He advocates for others to place these circumstances in perspective while maintaining understanding that other people may not utilize this coping strategy.

**Rationalizations: gaining advantages in having disability.** While some participants focus on the positives in their lives, some on how disability has saved them from negative outcomes, and some focus on how others have it worse, still others focus on gaining advantages due to having disability as the following quotes suggest: "Well you certainly get a front ringside seat everywhere" and "there are some advantages if you're out in the community some people... do give you like certain discounts on certain things." While a few participants rejected this aspect and preferred to not to have this type of recognition, others enjoyed the 'perks' of being able to have a pit position at a Springsteen concert, or a trip to Disney World through the Make a Wish Foundation. In



addition, others recognize opportunities for involvement in the community showcasing their skills as IWDD such as Special Olympics, wheelchair dance, and other events.

**Spirituality: for a purpose.** Some IWDD recognize their lack of culpability for their disability. These individuals were born with their disabilities and did not acquire them through engaging in reckless, dangerous behaviors. Through no fault of their own they have their disabilities and seek to understand the reason why this happened to them. As they understand that their condition has placed limits on their ability to participate in a full range of life's activities due to various social and environmental barriers, they are imbued with a sense of grief and loss.

Many who cope with grief seek answers to help them cope and adjust to their loss; IWDD may grieve and seek answers by linking their condition with a purpose in order to help put things in perspective. As one participant states, "Sometimes I'm I wonder why I'm this way. Why did this happen to me? I have a purpose in this life." Others find meaning in connecting their condition to a higher power. Frank is a devoutly religious man. He very articulately reflects on his condition:

Once I became a Christian I realized that as hard as it was for me God knew what was going to happen so he had these filters. Because sometimes I feel I would be able to influence people more but on the flip side some people are more influenced because of my wheelchair...the fact that I'm in a wheelchair and the second side I would not change it for the world because just knowing how God made me and knowing how that impacts people is really beyond anything I can even comprehend...Spiritually...Because they look at me and they see the problems that I have but they listen to me and and they think 'how can how can

he be so positive ...he must have something that we don't have I wonder what it is?' Then I can then that's when I can share with them that I'm a Christian and I'm going to give my testimony.

Tanya a bubbly, young woman with CP engages in meaning making on why she has her disability:

Because I have a mission in this life that I'm capable of doing that and why not take advantage...that I have to make a change because I'm too tired of seeing people suffer I want them to smile and to feel that positive weight of (?) angels that are willing to help them and that's what I want to be like their little angel like their little light...Because of my prayings and my beliefs that will happen with time...so I have my own beliefs... I have a purpose in this life so I want to protect that through my art...

In summary **self-recognition** consists of three axial codes, the first of which is comprised of: Created Rationales. Open codes under this axial code include: *Why me?*, *Rationalizations (Staying positive, It could be worse, gaining advantage)* and *Spirituality: for a purpose*. Participants focus on the positive aspects and rationalize that they could have it much worse. In addition they engage in meaning-making processes of attempting to understand why they have their disabilities and linking their condition to a higher purpose. Participants manifest awareness of their disability identity and seek to develop responses to cope with their sense of differentness and separation from the community at large. They incorporate different strategies to achieve this meaning-making culminating in adjustment to their condition. Focusing on the positives, such as creating

rationalizations, using their disability status for gaining opportunities or establishing a disability hierarchy assists them in finding purpose and meaning in their lives.

The next axial code under the subcategory of *self-recognition* is that of Hierarchy. Holding identities that are valued by society provides a means for IWDD to affiliate with higher social categories. This is a strategy which has been found to enhance one's sense of self and overall well-being (Deaux, 1993; Nario-Redmond, Noel, & Fern, 2013; Roccas, 2003). Participants in this study seem to recognize this process and seek to align themselves with positively viewed and elevated social roles such as those of a mentor/role model or as an educator/advocate. IWDD understand that even within their community, there is a hierarchy based on cognitive ability, physical abilities and social roles.

<b>Hierarchy</b>	
OPEN CODE	Example Statement
High functioning vs Low functioning	I just think that if somebody's labeled a certain thing like that if they're labeled high functioning I might take that as well maybe they're on my level...
Creating Higher Social Roles	
-Helping others	I really want to make a difference in people's life.
-Mentor/Role Model	I love that feeling of being able to you know be there for someone. A role model... and an inspiration.
-Educating Others	I want to show the world that it doesn't matter who you are or where you're going to where you've been to where you come from and like what your situation is if you have a passion and a dream...
-An advocate	I like standing up for people when they can't stand up for themselves.

**High functioning vs low functioning.** Wang and Dovidio (2011) explored the multiple social roles that individuals with disability maintain in the face of societal myths and misperceptions. Such misperceptions include the notion that IWDD “lack autonomy and agency” (pg. 123); they are perceived as lacking competency i.e. they are childlike and naive and as such, relegated to lower hierarchical social categories associated with lower status in society. Their research sought to understand how people with disability react in response to stigma and stereotyping processes in order to try to counteract these negative social interactions. One suggestion they propose is to ‘prime’ (i.e. place emphasis on) social roles or identities which are perceived in mainstream society as holding more valued and positive associations. It appears as if participants in this study react to their situation similarly. For example, participants sought to adopt such social identities as being a mentor, an educator, a role model to perhaps counterbalance other lower categorical roles such as being a patient.

This process (of emphasizing more valued categorically perceived social identities) fits with assumptions underlying Social Identity Theory (SIT). SIT proposes that people strive to maintain positive self-images that is to say that people affiliated with devalued groups tend to identify with groups perceived as maintaining higher social status (Roccas, 2003). If we posit that belonging to a group of individuals identified as having disability incurs negative associations, it is reasonable to expect that those affiliated with that group would seek to ascribe to other groups that have more positive associations.

These data indicate that participants seek to align themselves with groups of higher social status in relation to others. IWDD in this sample elevate their social roles

through developing a hierarchy of functioning levels i.e. “high functioning versus low functioning” peers. This is substantiated by comments by Carl as he reflects on his struggles in relating to others in his group home, he states “I do understand that through no fault of their own that they have different varieties of disability [from me] and what they can understand ... [referring to the other residents’ cognitive abilities].” Doris, a woman in her mid-fifties, is also a group home resident who has struggled in relating to her housemates. She acknowledges political correctness in some labeling processes “You’re not supposed to say this anymore but I don’t know how else to put it, the students there were not high functioning...I have felt like their cognitive abilities are not up to the same level [as mine].”

In addition to cognitive hierarchies, there are some who create hierarchy based on physical abilities. Here I present an excerpt from an interview with Luis, a man on the lower end of the continuum of cognitive abilities who has more physical abilities in comparison to others in his group home. He reflects on the positive aspects of having disability:

Bonnie: Are there any good parts about being [having disability]?

Luis: Me me

Bonnie: Me? What about you? Tell me more what you mean by that.

Luis: It’s good... Because I’m (indecipherable) proud...I’m proud of me...

Bonnie: Okay and why are you proud of you? ...

Luis: I do do do my my self. I do myself.

Luis goes on to proclaim his pride in being able to dress himself. While this achievement is modest by typical standards, in his group home, this is a useful skill.

Many of his peers in his group home are unable to do so. Thus he creates a hierarchy based on his physical abilities. His sense of pride in accomplishment was in comparison to others who are more physically disabled and are unable to dress themselves. These are the individuals with whom he has the majority of his social interactions.

**Creating higher social roles.** Several participants identified goals of being a role model/mentor/educator in relation to others. Asserting “But there’s a positive part to it ...Being in a wheelchair helping other people in a wheelchair too makes me a better person,” or “Helping kids with cancer. I go on the internet and talk to kids on the internet about their cancer what I can do for them and try to make it better for them,” situates the IWDD as “one up” and able to help others.

Allan has struggled with significant medical issues requiring months of bed rest at times. He reflects on his impact on others as a mentor/role model: “I would like to know that in some way, shape, or form that I touched some people; that whether it be positive or negative in some way shape or form um I gave them something.” While several adopt the mentor role, some participants seek to assume an educator role in order to educate nondisabled others, and in this manner become an ‘educator.’ These participants seem to be intuitively aware that by educating others who do not have disability about their condition or developing a personal relationship with them, that may serve to break down others’ fears and misperceptions about disability as the following excerpts illustrate. First, Sofia, a fiery Latina young woman expresses anger at a restaurant host who refused to seat her and her companions:

Oh I was pissed because I'd rather him be open minded to things than be close minded and be ignorant and be afraid to ask a person a question about why they're in a chair or why they have a disability or whatever...

And Blair, a young woman who has CP maintains an idealistic outlook as she speaks about educating others in a more global perspective:

I want to show the world that it doesn't matter who you are or where you're going to where you've been to where you come from and like what your situation is if you have a passion and a dream.

While Sofia seeks to advocate for social justice and her human rights, she speaks about educating a specific person who is stereotyping her and, in effect, diminishing her as a person. Blair, on the other hand, reflects on a wider, diverse network to receive education. Both speak of having motivation to assist others in learning about their experiences and intuit that by others gaining better understanding and appreciation, this paves the way towards tolerance and acceptance in the wider social community.

Various protective aspects are associated with ascribing to higher status social categories (such as being an educator or an advocate) and achieving a sense of social inclusion. These protective aspects consist of enhancing positive affect (DeWall, Twenge, Koole, Baumeister, Marquez, & Reid., 2011), impacting quality of life (Bayram et al., 2012), decreasing negative affect (Buckley et al., 2004) and facilitating an overall sense of well-being, health and happiness (Baumeister et al., 2005; Mason, Timms, Hayburn, & Watters, 2013). Participants in this study adopt this protective strategy and elevate themselves into higher perceived social categories in relation to their peers.

The next subcategory under self-recognition consists of IWDD *gaining understanding* over time and experience. As they gain understanding about their ‘differentness’ and how their life experience may differ from others in general society, they strive to put their situations in perspective.

### Gaining Understanding

OPEN CODE	Example Statement
Learning from experience/maturation	<p>Well from my experience (laughs) it taught me a way of living. I hated it growing up but it helps me learn that...I have to fight through every battle to be successful.</p> <p>I learned from it [having disability] and I’m the person I am today because of it so...</p> <p>I think it’s made me a better person now because I’ve learnt from my mistakes just because I have a disability doesn’t mean I haven’t done things that normal people have done.</p>

**Learning from experience/maturation.** Allan has had to deal medical setbacks related to serious skin break down issues necessitating long stretches of bed rest. He puts a philosophical and positive slant on his evolving perspective:

I think it helped me grow up faster. I think it helped me mature a lot. Sixteen, seventeen years old, you know how old are you know sixteen you know seventeen think like someone of this age and if you’ve been through what I’ve been through, seen everything that I’ve seen, it opens your eyes you know... You learn as you get older... I’ve learned a lot of things that I never knew about myself... I’ve learned to value things in life that I never thought I would.

Henry shares how he’s learned from his experiences. He states “I learned from it and I’m the person I am today because of it.”



The above quotes indicate that individuals with significant disabilities are reflective and gain understanding over time of their situations utilizing positive coping strategies to frame their experiences. They are able to use life experiences to learn more about who they are within the context of having disability, as well as in relation to the other identities they maintain within their self-concept apart from their disabilities. Specifically, developing a sense of recognition about their various selves (roles, identities, personas) within their self-concept, separate from having disability, is a process that can only occur through exposures to, and interactions with, their social environments over time. Maintaining complexity of self-concept consisting of multiple valued roles in addition to a strong disability identity is important for resilience and adaptation to environmental assaults such as loss and social exclusion.

Gaining experience with having disability and recognizing that as a part of other aspects of their self-concept helps participants to place their disability identity into perspective. This is believed to enhance self-esteem (Cast & Burke, 2002) and sense of well-being which has been associated with self-esteem (Rey et al., 2013). Recognizing the need to take ownership or control over one's own sense of well-being is articulated by Sofia who has struggled with serious emotional problems. She posits "I'd be the same unhappy person and feeling alone and unhappy but come to find out I found out that within myself that the only person who could make me happy was myself. I'm still learning that."

The final subcategory under self-recognition consists of IWDD owning their *'disability identity'* over time and experience. Assumptions of SIT (Social Identity Theory) include that people strive to maintain positive self-images by identifying with

groups perceived as maintaining higher social status, and the study participants speak of the positive aspects of living with disability. In essence, they elevate their status of having disability from a previously devalued group, to one that has traditions, culture, and power. This reaction mirrors the ‘disability pride’ movement characterized by individuals embracing their disability identity (Nario-Redmond et. al., 2013).

### Developing a Disability Identity

OPEN CODE	Example Statement
Disability acceptance	I’m proud of me. I wouldn’t change it if I could.

**Disability acceptance.** Research supports the premise that group identification enhances self-esteem and provides protection against environmental assaults such as loss or social exclusion (Thoits, 1985). Individuals are inherently motivated to belong to social groups; some suggest that this a biologically derived need and that those who experience social exclusion suffer emotionally when they do not ‘fit’ with socially valued groups (Baumeister et al., 2007; Charmaz, 2008). The process of developing cognitive self-appraisals in this sample of IWDD seems to support this premise. Shakespeare (1996) has suggested that developing a sense of ‘disability pride’ coincides with adaptive/protective and empowering paradigms.

Bogart (2014) discusses the manner in which achieving pride in a ‘disability self-concept’ may have more value in adaptation to disability than in trying to ‘normalize’ individuals through a rehabilitative lens. This research examined the difference between adaptations to congenital (i.e. developmental disability) in contrast to acquired disability. People with congenital disability were found to have more positive disability self-concept

and satisfaction with life compared to those with acquired disability. Disability self-concept served to mediate the differences in satisfaction with life between those with congenital vs acquired disability. Self-concept here is defined as a multidimensional entity which includes: self-esteem, group identity and self-efficacy. Disability self-concept arises out of affiliation with disability as a stigmatized social group (similar to processes related to minority group affiliations). Their findings indicate that satisfaction with life was associated with disability identity and disability self-efficacy. Disability self-efficacy is defined as the ability to manage tasks affiliated with one's disability in the accomplishment of one's goals (Amtmann, Bamer, Cook, Askew, Noonan, & Brockway, 2012).

Participants appear to incorporate this process within their cognitive self-appraisals. Participants were unable to reply to an early interview question of: 'how is your day to day life affected by your disability?' because they have no life experience without having disability. This question was quickly revised to 'how do you think your life might be different if you didn't have your disability?' 'Myself as someone with disability' is a primary identity for participants. Such a significant aspect of self-concept cannot be rehabilitated or suppressed. An alternative approach would be to embrace this 'disability identity' and participants reflect this process in their commentary. As Sofia articulates in response to 'would you change it (having disability) if you could?': "I wouldn't change it...Because whether I have a disability or not, I am who I am, it's part of who I am. Whether I walk or not, that's fine."

In summary, Self-Recognition involves processes related to IWDD engaging in meaning-making and creating higher valued roles/identities for themselves which become

part of their self-concept. Research indicates that self-regulation and cognition may be impaired due to social exclusion (Baumeister et al., 2005). The premise underlying this research is that the need to belong is related to happiness and well-being. When people are rejected from close social connections, they experience a broad range of emotional and psychological distress (Baumeister et al., 2005). This framework provides an underlying rationale of why IWDD seek to create social identities within which they are embraced and valued. By adopting positive, valued identities and elevating their disability status to one of empowerment and regard, they develop connections where they feel included, experience positive regard and sense that they belong. The negative effects of exclusion have been well documented in the literature (Baumeister et al., 2005); alternatively there is protective value in connecting with social groups that are welcoming.

Participants make meaning of their condition and frame it in positive, empowering perspectives. Participants engage in creating rationales explaining why they have developmental disabilities (i.e. “there must be a reason”), assuming higher valued group affiliations (e.g. “I’m a role model, an educator, a mentor,” etc.), learning about life over time and experience i.e. ‘gaining understanding’ (maturational processes) and finally recognizing their disability identity with a sense of pride and ownership.

The next subcategory within this theme of Recognition relates to ‘how others see me.’ This is an axial code (which actually becomes a task for participants to navigate in the final theory) and is further subdivided into perceptions related to ‘known’ vs ‘unknown’ others. Participants’ reactions (to how others see me) differ based on whether the person was considering someone who s/he had familiarity with vs someone they came

into contact with in the community. Thus, these reflections will be presented separately and then woven together in the resultant theory.

### **Recognition in Response to Known Others**

Many social scientists have provided insight into the dynamics governing interpersonal relationships at dyadic and group levels (Heider, 1958; Weiner, 1983). According to this research, individuals need to be motivated to individuate others who are associated with lower social categories. To individuate in this context means to recognize the person as a valued individual with unique qualities, not just as a member of a group. Gaining familiarity provides the basis for individuating and ascribing specific (positive) characteristics to another and has been posited to break down stigmatizing barriers constructed by stereotyping processes (Reynolds et al., 2000). Stereotype is a result of classifying types of people to save time and energy. When people become known in more detail in their social interactions, stereotyping is less likely to occur (Crisp & Turner, 2011).

When known to others, IWDD are seen for more than their visible disabilities. They become three dimensional persons comprised of both positive and negative attributes with talents, personality traits, and interests. This can pave the way to discovering shared interests and developing relationships. However, one caveat exists to this phenomenon; people need to be motivated to individuate unknown others. Those perceived to be in lower social categories (like IWDD) are less likely to inspire that motivation in others, and therefore that individuation is less likely to occur.

Known others (those who already know these participants) comprise a group consisting of: family and friends, coworkers (for those who work in the community),

volunteers who help out at the residential facility, and caregivers. Known others see the participants in a three dimensional perspective. These people have already become motivated to individuate the IWDD due to family ties, being a work associate, having an altruistic motivation to help others (as seen in the volunteers), or sharing an interest such as art.

‘Relationships with family and friends’ is the most frequently referenced code in the interview transcriptions identified in one hundred coded responses. Participants value their interpersonal relationships and when unable to be with biological families, seek to reinforce relationships by creating surrogate family from their MEC (Medical Educational Center) peers and staff.

#### **How (Known) Others See Me**

OPEN CODE	Example Statement
With respect/	People can be positive of things people and things of our condition.
With appreciation	People say I’m wise beyond my years. People say they could sit there and talk to me for hours.
As a normal person	They [arts access facilitators] talk to me like I’m a normal person.
Creating surrogate Like “MEC” Family	They’re like my family...they don’t judge me.

**With respect/appreciation.** Participants appear to develop positive cognitive self-appraisals based on how they are perceived by ‘known others’ such as family, friends, caregivers and peers. Specific examples of positive roles/attributes include the role of: ‘myself as a son/daughter’ associated with attributes such as ‘being valued’ and ‘respected’ as a person, and being understood and not labeled with preconceived judgments. Allan reflects on a close relationship he had with a woman:

No, no she didn't have a disability. She was very embracing you know towards what was going on around me cuz sometimes it's very hard you know to have relationships. To go up to a girl and get them to understand my disability and you know not just label me as someone who is in a wheelchair.

Henry has a part-time job at a minor baseball league. Here, he speaks about the adaptation to his wheelchair. The wheelchair needed to be adapted to accommodate his sale items; likewise his coworkers responded to those adaptations with both envy and acceptance:

I have it on my tray and uh actually I get a lot of a lot of um good ribbing from the other vendors saying that they wish they could have something like that so they could you know sit around sit down and still do their job.

Both of the previous quotes indicate that by achieving familiarity, understanding and knowledge, known others appreciate and value participants apart from their disability. They become fully fleshed individuals with distinct personalities and that builds bridges for the development of interpersonal relationships, just as with any 'normal' person. This concept of 'being normal' and being seen as normal is crucial for IWDD to achieve in relation to others' perceptions of them as the next section indicates.

**As a normal person.** Participants appreciate the familiarity with which known others perceive them as three dimensional human beings despite their disabilities. Sofia is a gifted wheelchair choreographer and performer. Here, she refers to her niece rooting for her during her wheelchair ballet performance. Even though her niece is aware of her 'differentness,' she sees her as a whole person, her auntie, her 'Tee Tee'.

Yeah I mean my niece knows Tee Tee can't walk. Tee Tee has a different way of getting around. Yes, Tee Tee has to sometimes crawl on the floor because Tee Tee can't get into certain rooms, but Tee Tee is perfectly capable of getting around. Tee Tee means aunt.

Shannah, a young woman with CP, uses a voice communicator device. She types out "MY MOTHER SHE DIDN'T BABY ME". She is referring to the fact that her mother did not infantilize her. Her mother placed the same expectations on her as on her 'normal' siblings. This was something that this participant appreciated as helping to make her a stronger person. She was glad not to receive special consideration due to having disability and instead be treated as everyone else in her family was treated.

Being treated normally was a theme expressed among participants as they described their relationships with known others. Normality is a relative conceptualization and by being treated as 'normal,' the participants become incorporated into whatever social group they are interacting with at the time. Participants recognize this variation in perceptions of normality. Jaleel muses on these variations in perceptions: "That's what I think; nobody's actually normal... They can say they're normal but no one is actually normal."

Being perceived by others as a normal person is a frequently articulated goal among the respondents in this study which might suggest implications for achieving a sense of self-efficacy as defined by Bogart (2014). "Being treated like everyone else" was coded thirty times and "Being normal" was coded twenty times throughout the transcriptions. This again speaks to the need for inclusion and perhaps the protective aspects that inclusion may inspire.



Participants desire the same level of acceptance among the general population (i.e. with unknown others), with less successful results. Some seem to understand that decreasing social distance and allowing others to gain familiarity with them would help combat misperceptions that exist about people with visible disabilities. Sofia remarks on this familiarity in terms of having volunteers at the residential facility: “Um I think in certain aspects...like with volunteers it opens up their eyes that we’re just like normal people.” A Jewish man, Maury who resides in a group home, reflects on how he is perceived and received in his temple congregation: “Knowing that when I go to temple, they don’t really look at the chair...They’re always happy to see me there.” He clearly perceives this as group acceptance and as a positive aspect of his life.

Joe recently moved back to the MEC from a group home after suffering some serious medical setbacks requiring a higher degree of medical supervision. Here, he reminisces about a previous job he held at a local bookstore prior to his medical condition deteriorating. He speaks about what he found enjoyable in working there: “I worked at Borders... [I liked] the atmosphere, the people.” Joe enjoyed the camaraderie of his coworkers in addition to being a valued member of his Borders’ team. Being perceived as normal reflects participants’ desires to be treated by others as they would treat people without disabilities. Participants feel normal when others place challenging expectations on them, accept them as part of their group, and perceive them as three dimensional persons, not defined by their disability.

**Creating an MEC surrogate family.** As a function of living apart from their families of origin at a residential facility, supervised apartments or group homes, IWDD’s peers and caregivers become ‘like family.’ This need to feel connected to others who

know one intimately transcends biological ties. To paraphrase a Crosby, Stills & Nash tune, ‘when you can’t be with the ones you love, love the ones you’re with.’ Residential participants create surrogate ‘family’ relationships out of their MEC peers and caregivers. These become “my MEC family.” Allan is very conscious of the way he creates this surrogate family: “Yeah yeah definitely I’m when I like get close to somebody I tend to like adopt them because like you know family.” Shannah types out on her voice communicator device her feelings about her PCA (personal care assistant) “SHE IS LIKE MY SISTER.”

Twenty-nine codes relate to ‘like family,’ thirty-two to MEC peers and twenty-seven to MEC staff. “He’s like my little brother,” “she’s like my little sister,” and, “I feel like MEC’s like a dysfunctional family,” are quotes which occur throughout the interviews. The specialized level of care available at the MEC means that some participants may be located very far away from their families of origin. Henry muses on his relationships at the MEC while maintaining an awareness that these may fall outside the boundaries of acceptable worker/patient relationships: “I have a lot of family members at MEC. I wouldn’t advertise them though you know I don’t want them to be accused of favoritism and get that person in trouble you know.”

Participants are cognizant of the fact that ‘known others’ see them as people apart from their disabilities. They prize those relationships with others who treat them normally and value them for their strengths, talents and other personal attributes. As one young man reflects on his relationships with his PCAs, “They talk to me like I’m a normal person.” Participants seek to strengthen bonds by assimilating MEC relationships into their family systems to counteract being separated from their families of origin.

## Recognition in Response to Unknown Others

In contrast, cognitive self-appraisals in response to unknown others generally have a negative taint. Participants are aware of stares and reactions when they are out in the community in contact with strangers. This contact with the greater community magnifies their sense of ‘differentness.’ Many respondents spoke of others ‘seeing the wheelchair.’ They were angered and disappointed as they sensed fear and misperceptions on the part of people in various venues such as malls, restaurants, etc. As a result they perceive themselves as unaffiliated with and stereotyped by the greater social environment. ‘How others see me’ was coded sixty times throughout the transcriptions.

### How (Unknown) Others See Me

OPEN CODE	Example Statement
‘Seeing the wheelchair’	It has all the stuff to do with seeing the wheelchair... They’re wondering why I’m in a wheelchair.
<u>Being Stereotyped:</u>	
As ‘stupid’/Being underestimated	I was always called stupid by other people.
As different (alien/weird)	Because I’m in a wheelchair and they look at me weird. That we’re weird aliens and we’re not human you know.
With judgment	I used to do rhythm gymnastics but I quit that because that got too hard for me. People were judging me.

**Seeing the wheelchair.** Grace, who has CP, articulates her experiences in trying to learn to walk and the impact that being in a wheelchair has had on her life. She is aware that having a visible disability attracts negative attention from unknown others. When asked what would she change in her life if she could, her response involves being

out of her wheelchair. She is sensitive to the fact that when she is out of her wheelchair, she does not get the weird looks that she gets when seen by others in her wheelchair. She states:

Be out of my chair more. Like when I see other people walking, it brings me down. Like if you've never walked before, it would kinda bring you down... people don't look at me like weird [when I'm] out of my chair.

She goes on to speak about 'being judged' by others. Grace recognizes that when others do not have familiarity with her or her condition, this sets the stage for unknown others' misperceptions. She states, "People were judging me because they didn't know anything about my disability."

**Being stereotyped.** The next few quotes indicate that participants perceive that unknown others assign stereotypes to them based on their physical disabilities. First Jaleel shares "Other people, it's not maybe like, well people who work with me know me and know I'm a normal person. People don't know me outside." Sofia expands on her sense of discrimination derived from stereotyping processes employed by unknown others. Here, she relates an interaction in a restaurant where a host refused to seat her and the group of people she was with:

They see a Hispanic man, a black woman, and a Hispanic woman which is me in a wheelchair...What is this discrimination? You see a black woman, Hispanic man and Puerto Rican woman in a wheelchair? What is this discrimination? What is this prejudice? What is this prejudice day or something?

People with disabilities are perceived by some others in society as lacking autonomy and competency. They are often stereotyped as being intellectually inferior and subsequently are devalued by unknown others.

**With judgment.** Several participants report being judged and seen as ‘stupid,’ underestimated, and overlooked. As one person states “Don’t ever underestimate a person in a wheelchair” and another person states, “If people do overlook me they’ll never know what I can give versus anyone else.” Other common stereotypes include infantilization and dehumanization (Capozza et al., 2013; Wang & Dovidio, 2011). These stereotypes include notions that IWDD are ‘different,’ “an alien,” “contagious” and such stereotypes then lead to protective reactions on the part of parents in the community towards their children. As Shannah types out on her a voice communicator “PEOPLE THINK PEOPLE THINK WE DON’T... HAVE A NORMAL LIFE.”

Having a visible disability is associated with great stigma and stereotyping processes. “Seeing the wheelchair” was coded thirty times throughout the transcriptions. “[I would wish] for people to realize we’re people first, not the wheelchair. You get weird looks when you’re in your chair,” “I don’t like when they look at me weird.” Grace is particularly sensitive to others’ reactions and stares in public settings; she reflects “Because I go to the mall, sometimes people look at me like I’m weird and I feel like I’m just like you.”

Ivan uses a communication board. He points out symbols to indicate his perceptions of others who maintain misperceptions of his capacities based on his disabilities (he is non-verbal and in a motorized wheelchair). In response to a question about negatives in his life, he conveys the following message (Susie is a teaching

assistant who was assisting me in understanding the complicated code system used in Ivan's communication board).

Ivan: People.

Bonnie: People? Any people in specific or people in general? People in general are negative aspects?

Susie : (counting) some (counting) some people

Bonnie: Can you give me a context...what kind of circumstances they're negatives?

Susie: (counting) do (counting) dumb

Ivan goes on to explain what he means by 'dumb.' He describes others as being 'dumb' because they underestimate his abilities due to his being in a wheelchair and unable to speak. Ivan is an intelligent man who is a talented artist and has his own greeting card company. He is a motivational speaker for people with disabilities.

In summary, participants maintain multiple complex identities related to various social contexts. These identities are described by personal characteristics and social roles which have associated features (attributes, characteristics, descriptors). The combination of identities and features, I refer to as cognitive self-appraisals. These arise as participants become aware of their differentness and attempt to make meaning of their place in the world and their reactions to their disabilities. At the intrapersonal level, cognitive reactions encompass enhancing their identity complexity by creating rationales for their condition, creating hierarchies (ascribing to higher perceived socially valued identities), gaining understanding over time and experiences, and in developing an empowered 'disability identity.'

At the extra-personal level, IWDD's reactions are relational with respect to 'how others see them.' With known others, the reaction to the relationship is positively valenced as IWDD refer to being seen with respect, with understanding, and with appreciation. With unknown others, the participants have a sense of being socially ostracized due to having a disability that others can see.

Participants refer to others 'seeing the wheelchair.' This marks the IWDD as different from normal people in society. The participants understand that when unknown others gain familiarity with them, social barriers related to misperceptions and stereotypes can be broken down. When IWDD cope with their condition, this reflects a Response which may be adaptive (Resiliency) or problematic (Pain/Despair). The adaptive response is derived from maintaining features described by positive attributes relative to various identities. The alternative to developing adaptive coping strategies is Pain/Despair. This process will be examined in the next thematic category of "Response."

## **Chapter 5. Response**

Response represents the second overarching theme in this project; it encompasses the emotional aspect of participants' experiences in their social contexts. In Recognition, participants develop cognitive self-appraisals. Cognitive self-appraisals are comprised of the combination of identities with their associated features. Features can be positive or negative in relation to those identities. For example, an identity one may hold is 'as a female,' and some features the person might associate with that identity can include positive features such as: 'empowered,' 'strong,' and 'affectionate' or negatively associated features such as: 'suppressed,' 'domesticated,' and 'powerless.' IWDD (individuals with developmental disabilities) who maintain identities associated with self-perceived positive features may exhibit an adaptive Response (to environmental challenges such as loss, exclusion and ostracism). I propose this aspect be considered as a possible means towards IWDD achieving a sense of well-being.

Emphasizing positive features associated with multiple identities may have implications for enhancing identity complexity and subsequently impacting overall sense of self-acceptance, acceptance by others, well-being and adaptive adjustment for an IWDD. In Recognition, these cognitive self-appraisals reflect external input from 'how others see them' in relation to known and unknown others. The theme of Response articulates the emotional responses utilized in order to achieve self-acceptance (at the intrapersonal level), and adapt to inclusion vs exclusion (at the extra-personal level). The positive self-appraisals analyzed in Recognition are comprised of important identities within one's self-concept and IWDD's perceptions of themselves when enacting those roles. In Recognition, this involves the way IWDD think about themselves. In Response



this process involves the way IWDD feel about themselves when they think about themselves enacting these various identities within their self-concepts.

Coping and adaptation are associated with maintaining positively valenced features in relation to those identities. Alternatively, negatively valenced features would imply adjustment issues which may include non-self-acceptance. Research suggests that the ways people with disability react to their perceptions of prevailing stereotypes can be instrumental in combating stigma (Wang & Dovidio, 2011). I propose that IWDD encounter a critical task at the intrapersonal level in Response that involves their emotional response and adaptation to the different cognitive self-appraisals; I term the positive adaptation as *Resiliency* and the difficulty adapting as *Pain and Despair*. Coping mechanisms, maintaining motivation to achieve goals, resiliency statements and overall emotional adjustment are encapsulated by this domain.

### **Response in Relation to Intrapersonal Experiences**

#### **Resiliency**

OPEN CODE	Example Statement
What motivates me - goals for future	I'll get through it. I think about things that, like, I want to be doing when I get up, so you know, that helps motivate me.
Having resilience	If something knocks me down I get right back up, dust myself off, and get right back to it again.
-Defiance	IT DOESN'T STOP ME DO ANYTHING I WANT TO DO.

**What motivates me.** Some participants articulate “what motivates me” as a means to cope with their disability and living circumstances. Markus and Wurf (1987) describe motivation as an important function within one’s self-concept which moves that person towards action. Motivation, in essence, is a drive to move on with life despite

barriers (social, environmental and physical) which may present obstacles for achieving one's goals. Allan, who has spina bifida, has had to endure months of bed rest due to recurring wounds. He has developed a philosophical stance on his condition although he is understandably depressed at times. Here, he reflects on what motivates him:

I'll get through it. I think about things that I want to be doing when I get up, so you know, that helps motivate me and you know what's the purpose of being negative or being upset about it?

Blair thinks about the impact that disability has had on her life, she reports "I hated it [having disability] growing up, but it helps me learn that I have to fight through every battle to be successful." This statement indicates her motivation to overcome the challenges that having disability has presented for her. Carl explores connections between his interest in criminology and his family history of involvement in law enforcement professions. He reflects on how pursuing his interest in this profession has helped occupy his mind.

[I had gone] to college. One of the things I loved to do. I was a criminology major. Now my uncle, my cousin's a cop in NY, and my mom was uh a probation officer for a while and my cousin and my uncle were cops and firemen. Now because I was a criminology major, I had the opportunity to do a co-op and I did one in probation down here um that I really liked a lot. I actually had a caseload that I got involved with. I would go to the jail, get things ready for court. I really liked [that] a lot. It kept me busy, anything to keep me busy to keep my mind active, I don't mind.

Tanya and Sofia both articulate their motivation and drive to achieve their goals. First, Tanya states “But I know with my determination and my enthusiasm, I will make it all the way” and then Sofia declares:

I’m gonna reach my goals and reach my dreams whether they [family, staff] support it or not, and I’m not going to let anybody stop me. [Which] doesn’t mean I’m not going to reach my goals or I’m not going to drive or you know try to drive, or not have a relationship, or you know go skiing, or go water tubing, or water skiing, snow skiing.

The previous passages are examples which illustrate that maintaining motivation for achieving goals can be an adaptive Response to having disability similar to individuals without disabilities maintaining motivation to achieve goals in the face of challenges. Markus and Wurf (1987) propose that goals effectively mediate behavior by serving as information filters reflective of whatever setting that person is situated in at the time. Here again, the contextual antecedents of the particular social environment impact the motivation for achievement of specific goals. Hence, some of these goals may fluctuate depending on the social context.

**Goals.** Goals are wide ranging such as those expressed above by Sofia, Tanya and Carl and include: continuing education, getting a job, pursuing hobbies, getting married, and/or having children. All of these goals characterize traditional, typical goals that ‘normal’ people without disabilities strive to achieve. Perhaps maintaining goals that IWDD perceive those people without disabilities as valuing, enables them to feel like any person (including those without disabilities) and subsequently, provides them with a sense of normalization (Wolfensberger, 1983). The Principle of Normalization for

individuals with disability espouses that any person with disability is entitled to the same goals, experiences and opportunities as people without disability, in effect ‘the good things in life.’ Blair and Grace indicate these goals respectively: “I want to have babies and I want a normal life,” “I want to have kids one day, like I want to be a mom and a wife to someone.” Ivan also articulates this sentiment through his communication board:

Susie: (counting for Ivan) I want to get

Bonnie: you want to get

Susie: (counting) married, kids

Bonnie: So those are your hopes for the future?

Ivan: (Nods) yes

Blair describes her dream of becoming a fashion model. She is aware that many advertisement campaigns are now using models with visible disabilities in their ad campaigns.

Blair: Also modeling...I’m in the process of going out and finding a job

Bonnie: So you’ve been applying for jobs? Modeling jobs? How’s that been going?

Blair: It’s been awesome and I got a photographer and (indecipherable)

Bonnie: You had professional shots taken, right?

Blair: Well some are.

Bonnie: Some are professional and they’ve sent them out.

Blair: Well we are now in the process of sending them out...I love that, I love that, I love that [being a fashion model with disabilities].

Allan discusses his dream of becoming a counselor “I even thought about maybe being a counselor or being like a social something like in social services.” Kurt types out on his voice communicator his desire to move into a supervised apartment:

Kurt: I WANT MY APARTMENT

Bonnie: You want your own apartment; you live in a group home now?

Kurt: Yeah!

Jaleel wants it all! He states “I would like to have a job, I would like to have a girlfriend, I would like to go to college.” Going to college is often identified as a goal among the participants. For young adults, it is a normalizing goal as the next couple of quotes illustrate: “I plan to go to college,” “It’s definitely on my to-do list [going to college].” Others want to get a job or travel: “To get a job,” “Yeah go back to work, yeah I mean not only did I get paid but I got to travel more.”

Some goals expressed above are realistic and some are not likely to be achieved, contrary to the rationale outlined in the Theory of Normalization. The objective for an adaptive Response is to define and facilitate realistic (achievable) goals for IWDD. Markus and Wurf (1987) explore self-concept as a dynamic entity and analyze the various components from intra and interpersonal perspectives. At the intrapersonal level, they suggest that there are three main processes which mediate self-concept including: information processing, affect regulation and motivation.

Maintaining motivation towards achieving goals is important to achieving ‘desired selves’ (Markus & Wurf, 1987, p. 321). Desired selves are defined as what the person would like to become and can realistically achieve, thus having implications for the person’s sense of self-efficacy. As mentioned in chapter 1, self-efficacy is a

component of self-esteem within one's self-concept. Self-esteem relates to an individual's positive evaluation of himself (Rosenberg, Schooler, Schoenbach, & Rosenberg, 1995). Positive evaluations of self arise when the individual perceives him/herself as a person of value, or in other words, competent and efficacious (Cast & Burke, 2002). However, if goals are unrealistic and are unable to be achieved, people feel incompetent, have lower self-esteem and experience negative emotional responses such as anger, depression or anxiety.

For example, Jaleel has an outgoing personality and enthusiasm for life. He has been supported and encouraged throughout his life by his education and therapy teams. Compared to his peers at the MEC (medical educational center), he is in the top echelon of cognitive functioning, that of borderline mild retardation/normal intellectual functioning. His expressive language abilities and social skills make him appear to have much higher cognitive abilities than formal testing indicates. Despite his language abilities and social savvy, he cannot read nor do math, which are prerequisites for college admission testing. Many tutors and special educational modules have been used in order to assist him in learning to read, but he has neural processing issues which prevent him from achieving this goal. He struggles to accept this reality.

Jaleel has been pumped up throughout his life by well-meaning ancillary staff (i.e. therapists, educators, personal care assistants) that he should become a lawyer or a professional entertainer (he also participates in the MEC choir). In addition to the MEC staff, young, well-meaning volunteers visit in the evenings and on weekends. They have befriended Jaleel during their visits and become his Facebook friends. Through social media, he is aware of their college antics. He is excited and motivated to pursue college

studies and campus life, yet these seem to be unrealistic expectations. Social media do not truly represent all that being a college student encompasses. Jaleel places emphasis on the fun aspects and social opportunities at the expense of focusing in on the challenges of maintaining grades.

Jaleel's social worker has been attempting to direct him to more achievable, realistic goals, but Jaleel will not be dissuaded from his dream of attending college. Jaleel and his social worker are now exploring the possibility of trying out a course in a community college setting. Barriers exist due to Jaleel's need for special computer software to 'read' the material and 'write' his essays for him. Additionally, he would need help with transportation and he needs a personal care assistant (PCA) for his days in the classroom. Funding is always an issue and the special software, transportation, and the PCA are considerable expenses. He will not consider an online program. He seeks the full college experience. His head is filled with ideas of 'keggers,' parties, and fraternities from his volunteer friends. That defines for him what the college experience is like. He claims he understands about the challenges of entry level course work, exams, deadlines, etc. However his dream of college will persist until he is allowed the opportunity to try and inevitably fail.

Adopting a person-centered orientation involves having Jaleel identify his overall goals and then breaking those goals down into achievable short-term goals. Jaleel, however, spurns this approach. He feels he must try to achieve his ultimate dream of having an on campus experience. Only when confronted with the impossibility of achieving this dream will he be able to move on and become motivated to explore more realistic goals. Achievement of realistic goals results in a person obtaining a sense of

self-efficacy which enhances self-esteem and overall sense of well-being (Rosenberg et al., 1995); alternatively failure to achieve goals results in disappointment, and lower self-esteem.

Self-efficacy, along with self-esteem comprises the self-evaluative component of self-concept (Leary & Tangney, 2003), with identity complexity as the third part of self-concept as previously defined in Chapter 1. Self-efficacy is defined as verification of a group based identity which produces feelings of competency, self-worth and self-esteem. Further, confirmation of group-based identities indicates acceptance of the self within the group. Obtaining such group-based acceptance has been associated with the motivating factors which regulate behaviors in achieving goals (Markus & Wurf, 1987). I propose that maintaining motivation for achieving realistic goals is a component of resiliency. Motivation for achieving unrealistic goals does not promote resiliency but rather disappointment and lowered self-esteem. Other facets of resiliency include adopting adaptive defense mechanisms to combat trauma, loss and exclusion/ostracism to be further explored in the next section.

**Having resilience.** A second code under this theme includes ‘having resilience’. The next few quotes further illustrate resiliency statements: “[I] learned to accept myself,” “Um my most important message is ‘don’t let life get you down’,” and “I try to overcome it [my disabilities].” Participants embrace obstinacy as a defensive mechanism; they have to engage in many struggles in their day to day lives. They maintain an attitude that they have, and will continue to defy and overcome the various obstacles they encounter.



Coping statements were coded sixty-seven times and there were sixteen subcategories of coping such as coping; being resilient (twenty-two codes), coping: being spiritual (fifteen codes); coping: being busy (five); coping: knowing it could be worse (twelve); and coping: overcoming obstacles (three). Tanya, a talented and versatile artist, reflects on how being an artist has helped her in overcoming obstacles:

It's changed over time; it has progressed. I've grown as an artist. I've overcome many things, many obstacles in my life; yes, so art is everything to me. Art is my love you know. I wouldn't be the person that I am today, the young woman that I am.

Tanya mentions her struggles to overcome obstacles in achieving her dreams as an artist. She also recognizes that experiencing those struggles along with her 'artist identity' have impacted her sense of self in a way she greatly values. Maintaining resilience by utilizing obstinacy in the face of overcoming obstacles invokes a defiant attitude which many in this study incorporate as a coping mechanism as elucidated in the next subsection.

***Defiance.*** The previous section indicates that a certain level of defiance seems to promote resiliency. Some IWDD express a defiant attitude, "I will prevail," "Nothing stops me," "it's [disability] not going to stop me from moving on with my life," and "I can't give up" indicating an internal struggle. Many participants spoke of maintaining a need to "keep moving on" despite their disabilities and the various physical, health, environmental and emotional obstacles they face. Jaleel shares his philosophy: "Think of the positive things that you have and put your mind to it and keep it moving." Shannah speaks through her voice communicator; she spells out "NOTHING STOPS ME."

Tanya poignantly shares:

You have to make sacrifice in life to get where you really [want to go] in your life and [you need to take] some risks. Nothing is easy in this life. You have to try hard and remember don't give up. There [is] always a way to do something no matter how hard it really seems. Just go for it and surround yourself with positive people because anything is possible. You have to feel it inside of you though for real.

While a certain degree of defiance may promote resiliency, there is a tipping point where defiance in pursuit of valued identities that are unachievable actually hurts and diminishes resiliency. If resiliency is not achieved, then participants speak of frustration and the pain/despair associated with living with significant functional limitations and visible disability. Some participants harbor suicidal ideation at times. Some participants speak of the frustration at being dependent on others, having to be patient, and ultimately having depression, which ensues from their sense of helplessness associated with that degree of dependency. All participants are dependent for assistance with all activities of daily living and need twenty-four hour supervision by a PCA. They have chronic conditions that no degree of rehabilitation will ameliorate.

The next section will elucidate the anguish that occurs when the reality of having severe functional limitations becomes overwhelming. Individuals without disabilities who fail to achieve goals can often modulate negative emotions by adopting varied and valued identities (Cast & Burke, 2002). This Response is not always available to IWDD. They may have fewer options available to them when seeking alternative identities and activities that are valued. This means IWDD's coping strategies may be more limited when their expectations are unfulfilled compared to others without disability.

### Pain/Despair

OPEN CODE	Example Statement
Dependency	I wish I could take care of myself without having a PCA do everything.
Depression/ Loss of hopes for future/ suicidal thoughts	I had depression. [I felt] really really down.

I felt like I wanted to kill myself

**Dependency.** Dependency issues are powerful and are fraught with associated feelings of frustration and anger. Many participants speak of the limitations that are imposed on their choices as a consequence of their level of dependency. Doris, a fifty-four year old woman with cerebral palsy (CP) who resides in a group home, articulates her awareness that her functional limitations prevent her from moving ahead with her dreams of living in a supervised apartment someday.

Cuz they expect you to undress and dress yourself fully...they yeah they would expect you to take yourself to the bathroom which I'm not able to do, so I would like to change all that, even though I can't, so I could go there.

Doris goes on to reflect on what it is like to be dependent on others and having to wait at times for assistance with ADLs (activities of daily living):

You have different people taking care of you other than your family. You have to be more careful what's said and what's done. You have to be um because I'm not able to toilet myself, that's a harder thing, because when you have to go to the bathroom and you can't just get up and go, it's pretty uncomfortable.

Shannah types out on her voice communicator "I NEED HELP WITH EVERYTHING."

She goes on to reflect on her frustration with needing such a degree of assistance and

being limited in where she can physically go. The following dialogue is an exchange where she is responding to what life is like for her with her disability:

Shannah: W-A-I-T

Bonnie: Waiting, what kinds of things do you have to wait for?

Shannah: (grunts)

Bonnie: Everything? Everything okay and how does that make you feel? What's that like for you?

Shannah: P-A-I-N-N.

Bonnie: P-A-I-N pain pain waiting for everything is a pain and those are the obstacles any other obstacles that we haven't mentioned?

Shannah: (grunts) I CANNOT GO EVERYWHERE.

Tanya lives with her biological family in the community. She expresses what it is like for her to have to wait on others for assistance: "Every day is an obstacle for someone with a disability because you have to depend on others to get things done, it's a hassle." It is clear how dependency issues, chronic illness, and being separated from family and friends are frustrating, limiting and can ultimately yield coping difficulties, most commonly depression, in this population of IWDD.

**Depression.** Half of the participants in this sample (50%) are diagnosed with clinical depression. Most of the others express symptoms of situational depression at times during the course of the interviews. Helplessness, hopelessness, and an inability to verify valued identities (to be further explored in Reconciliation) associated with their condition can result in depression (Abramson, Seligman, & Teasdale, 1978). The next couple of quotes reflect the depression that some participants feel. As Tanya discloses

“I’m diagnosed with depression because all I do is cry.” Grace laments “Cause I was feeling sad, you know very depressed.” Depression also arises as a result of losses related to letting go of long held dreams for the future.

*Loss of future dreams.* As IWDD age, they become aware of how others their age (who are non-disabled) experience different life circumstances that seem closed to them. Many participants, as previously mentioned, maintain unrealistic expectations. When they finally let go of their dreams, they experience the loss of those dreams such as being able to walk, attending college, learning to read, or having children. Carl ruminates on the loss of his dream of having children:

There are things that I really wish I had that I don’t have, and like a kid or something. I don’t lose sleep over it, but like when I go, that might be it for my last name. So I’d like somebody to carry on my last name.

Carl is the only son in his family of traditional Italian immigrants. Family has strong emotional connotations for Carl. As he approaches his senior years, he notes that while not of crucial importance for him to have had a child to satisfy any paternal longings, he would have liked to have procreated in order to continue his family legacy.

The following interview excerpt is an example of how Grace acknowledges the loss of a long held dream of being able to walk:

Grace: I had twenty two operations to try to get me to walk, and back surgery too.

Bonnie: Okay and are you still moving along that road? Is that still a goal to walk?

Grace: Not in my book anymore...because I don’t see the point of getting my hopes up.

Bonnie: What was that like for you getting your hopes up?

Grace: Disappointing.

Grace expressed her feelings on this with a flat affect indicating her resigned attitude towards the loss of this dream. She has coped with this loss by adopting other roles that showcase her talents in a positive light and enhance her sense of self-worth and self-efficacy. Grace is a talented wheelchair dancer and painter in the arts access program. She expresses her losses through her poignantly conceived art works and has received wide acclaim and affirmation for these productions. However, devastating losses of future dreams can lead to feelings of hopelessness for some IWDD. These feelings, if unabated, can result in depression.

Mental health issues are more frequent for IWDD due to their functional limitations, lower ability to use protective defenses, and less opportunity for exposure to varied social contexts references. Having increased exposures to social contexts may offer additional options for realistically achievable goals. In addition, exposures to various social contexts may impact and increase identity complexity (which, as previously suggested, may have protective value in enhancing coping/adjustment). Conversely, less exposure to varied social contexts may have the opposite effect and may increase susceptibility to mental health problems such as depression and anxiety. Most participants in this study experience depression which in a few cases, leads to suicidal ideation.

***Suicidal thoughts.*** Some respondents acknowledge an impulse towards ending their own life as the next several quotes illustrate: “My LN (Lesch Nyhan), I want to kill myself,” “Thinking about killing myself when I was growing up because I had a disability, denial, didn’t want to accept the real truth, like why did this happen to me?,” “I wanted to basically off myself, kill, kill myself,” and “I WANTED TO KILL MYSELF.”

These excerpts are associated with severe feelings of depression, hopelessness and helplessness with their situation. Many of the participants receive psychiatric care, psychotherapy and take antidepressants to help alleviate their clinical depression.

Participants diagnosed with Lesch-Nyhan Disease (LND) are all in safeguarding equipment due to their propensity towards self-injurious behaviors (a symptom of the disease). Despite these precautions, individuals with LND have engineered ways to self-harm and even have delineated achievable plans for suicide when asked, as part of a suicide assessment. By positioning their heads and necks in their headrests in a certain way, they are able to cut off their air flow and risk suffocation. Any expression of suicidal ideation in this population has to be taken seriously and a plan of vigilant counsel and supervision immediately implemented.

Further impacting adjustment are Responses to extra-personal influences, specifically reactions of IWDD to known and unknown others. The next category is *Response to extra-personal influences*. Encapsulated by this category are influences that impact differentially depending on whether the relationship is with a person who is known or unknown to the participant. ‘How others see me’ has a profound effect on IWDD’s self-image as indicated in the theme of Recognition. The need to feel included and part of a group/unit is an important motivating agent expressed throughout the interviews. Hence, the task to be achieved at the extra-personal level is that of *Inclusion vs Ostracism*. Unsurprisingly, family and friends become an integral part of this process and their perceived reactions to the participants are much different from reactions of unknown others. This theme is further subdivided into interactions with known and unknown others.

### **Response in Relation to Extra-personal Experiences (known others)**

Known others (those with familiarity with the IWDD) generally accept the person with their disability, usually over the course of a lifespan. The sense of inclusion is encapsulated by the code ‘belonging/fitting in.’ Individuals feel accepted by known others in the community such as those encountered in their religious settings, work associates and by family and friends. In addition, “the Medical Educational Center (MEC) family” was another known relationship category. Relationships in the MEC are consistently described as my ‘MEC family’ as mentioned in Chapter 4. Participants living in the group homes or at the main facility spend more time with their MEC caregivers and peers than they do with their families of origin. As a result, they come to view PCAs, nurses, roommates, etc. as their surrogate “MEC family.”

#### **Inclusion**

OPEN CODE	Example Statement
Belonging/Fitting in:	Fitting right in.
-Relationships with family and friends including: ‘MEC family’	He’s my PCA and my friend...and I love him

**Belonging/fitting in.** Participants spoke about having a sense of belonging and fitting in with relation to known others such as family and friends as well as known others in the community such as work associates. IWDD, like people in general, are sensitive to others’ reactions towards them and if others are perceived as being warm, inviting and positive, this affects how they feel about themselves and their overall sense of well-being (Markus & Wurf, 1987; Richman & Leary, 2009). Research supports the notion that prolonged exposure to others who feel positively towards a person enhances



the well-being of that person; conversely, exposure to negative interpersonal reactions is associated with mental and physical health related difficulties (Baumeister et al., 2005; Pressman & Cohen, 2003; Williams, Neighbors, & Jackson, 2003). Here I examine whether these assertions are supported by these data with regards to relationships with family and friends.

*Relationships with my family and friends, including my ‘MEC family.’* As mentioned in Recognition (Chapter 4), ‘Being with my family and friends’ is the most frequently coded response from the interviews. Here in Response, the emphasis is placed on how being with family and friends bolsters feelings of inclusion and belonging. Henry is enthusiastic about his relationships with the fans and coworkers at his part time job at a local ball park:

Oh yes I have found from fans at the ball park to coworkers, some people are on my Facebook and you know it’s a very it’s a very welcoming environment. My bosses love me, my coworkers are excellent and uh the warm reception I get from fans on the first day of the season is very heartwarming. I often joke that I have more fans than the team.

As the next few quotes indicate, acceptance by family members helps participants cope with their disabilities. Allan reflects on the impact his mother had on him:

I mean uh she [his mother] was able to always be there for me, you know, growing up and pushing me, you know to not look at myself as a handicap. You’re, I hate to use this word, but you know like crippled, you know? Like she would say ‘you’re just like anybody else you can [do anything that] anybody else is doing, you know? Don’t let anybody bait you.’

Here, Allan voices his appreciation that his mother treats him with the same standards she uses with his siblings who are non-disabled. She counsels him that he is just like everyone else despite his disabilities. He credits her encouragement and normalization of his abilities with providing him with motivation to move on despite his limitations. Carl reminisces about others in his family who also have disabilities, and how he obtained hope and motivation from being exposed to their experiences:

You know, I use a wheelchair. It's noticeable but um I'm not the only person in my family that's got a disability and at times that, to me, was very helpful because I seen Megan, my cousin, do things that maybe I thought about didn't think I could do. But once I saw them do it, then I said, 'all right my expectations may not be so farfetched.' Like my mother wanted me to go to college.

Again, here it is evident that Carl is motivated by others in his family with disabilities achieving goals that he had not considered for himself. In witnessing their achievements, he felt motivated to pursue more lofty goals for himself. Maury considers the feeling of belongingness he has when he joins in with his temple congregation "and know[s] that...when I go to temple... [I] fit right in."

Having a job or being part of a religious congregation offers IWDD a bridge to traverse the divide of segregation from the wider community. Integration of IWDD into various social contexts invokes commonalities and shared interests with unknown others in effect, transforming unknown others into known others. This allows IWDD to gain familiarity with those in the community, break down preconceptions, foster relationships and rapport with others, and become accepted in various social domains.

As mentioned in Recognition, thinking about themselves as members of social groups provides protection in the form of resiliency against certain social-environmental assaults. When people perceive that others are accepting and maintain positive perceptions towards them, this affects how they feel about themselves, the quality of their interpersonal relationships, and their sense of well-being and life quality (Richman & Leary, 2009). Negative reactions from ‘unknown others’ include in part: stigmatization, avoidance and rejection. These reactions impact the rejected person’s ability to regulate behavior, affect, and mood (Baumeister et al., 2005) and will be explored further in the next chapter under: *Reconciliation in reaction to unknown others* under the axial code of Community Isolation.

Rejection from ‘known others’ such as uninvolved biological family and failed romantic relationships are counterbalanced by maintaining close, nurturing relationships and a sense of belonging in other more welcoming environments such as the MEC. However, there are threats to this sense of ‘family’ and community that consist of recurrent losses that occur due to natural attrition (staff leave for new positions, peers die at a higher proportion than in communities of individuals without disabilities). Recurrent grief is associated with frequent losses related to death in the MEC community. Such loss occurs at a higher frequency because of the fragility of IWDD’s medical conditions. In addition, grief associated with disenfranchised losses is often accompanied by a sense of rejection in this population, when favorite therapists, PCAs, nurses, and other staff leave to move on to other positions. These losses create emotional ‘responses’ associated with feelings related to being separated from family and friends, ‘known others.’

### **Being Separated From Family and Friends**

OPEN CODE	Example Statement
Rejection	People not treat you the same as you treat them.
Guilt	It's frustrating you want to blame other people; you feel guilty.
Loss	Okay, I have I had so many losses.
Anger	The anger that I feel towards certain people and everything so my temper could go off - sometimes it gets the best of me.
<b>Barriers</b> Finances/ Transportation/ Distance/Health/ Burden of Care	You want to be with your family they can't handle you anymore.

**Rejection.** Being separated from family/friends was a frequently referenced theme across interviews. Participants report feeling abandoned, rejected, and out of touch with their families and neighborhood friends. This was a distinct loss for them resulting in feelings of guilt and anger. Distance/transportation issues, finances, and just 'being busy' affect the ability of family members to visit. In addition, the burden of care that necessitated placement in the first place was cited as a reason why participants could not visit their families in their homes of origin. The next dialogue with Blair, a young woman with CP, exemplifies some of these concepts. She has a great deal of difficulty with verbal communication due to spasticity related to her CP diagnosis, but here she is creatively expressive.

Bonnie: And your family how far does your family live from here?

Blair: Maybe twenty-five minutes.

Bonnie: Twenty-five minutes, are they able to come and visit?

Blair: Yes and no, it's not far from here but they're so busy.

Bonnie: They're busy

Blair: ... they're in their own world...and I'm feeling (laughs) like I'm not in it.

Blair uses insight along with her wit to indicate that she understands that her family is busy and she is not included in 'their world,' that part of their lives. She makes an excuse for them but expresses this sentiment with a sardonic attitude indicating a hint of frustration, resignation, and regret. Henry reflects on what life in his dysfunctional family of origin was like prior to moving to the MEC:

Like I said, I grew up in a household where my mother was always drunk off her ass, pardon my language. My father was always working and so all I had was my Nintendo in my room. My mother would either be, you know, passed out drunk or hanging out with one of her guy friends in the other room and I would just be engaged in a game you know.

Henry expresses a sense of relief in escaping this dysfunctional home situation. He uses computer gaming as an escape and it has become an integral part of his life both in his dysfunctional home environment and continuing on to his admission at the MEC. For Henry, the MEC became a refuge from a hostile, explosive family environment.

Sofia thinks on her volatile relationship with her biological father "He's been in and out of my life my whole life." She echoes Henry's sense of relief in being able to escape from a high tension, inflamed family system. She relates:

Emotionally I feel close to them but in a sense, in a way, I don't because I try to avoid conflict and to avoid conflict I think it's best that I don't live at home because to uh avoid the confrontations that um we've had in the past.

Dysfunctional families, distance/transportation issues and burden of care are some of the circumstances that interfere with participants interacting with their families and

friends outside of the MEC community. Participants express frustration, anger, and in some cases resigned relief, at not having their families consistently involved in their lives. Oftentimes IWDD blame themselves for family relationships becoming estranged. This self-blame translates into guilt experienced by participants.

**Guilt.** Guilt at exacerbating family tensions, not living up to expectations, and being unable to assist families in need plagues many participants and serves to lower their sense of efficacy. Self-efficacy, as previously defined, is the ability to achieve goals. Carl is a middle aged man with CP who has resided in the MEC since early childhood and has recently moved to a community based group home. He is very aware of the struggles his family experiences as his mother ages and becomes a burden for his sister and her husband. He holds a role for himself, as the older son, to be the person responsible for coordinating care for his mother; this is a goal he is unable to accomplish due to his own disabilities. He expresses his guilt feelings at not being able to assist his brother-in-law with his aging mother.

My brother-in-law, he's great... and to the things he does for my mother you know is amazing. But you know sometimes I like to you know wish I could lessen the load for him a little bit just a little bit. Cuz he's got his own business and you know...I'll say look don't worry about her. I can get a ride I'll get a ride cuz it's usually like taking her to the doctor's appointments. He doesn't make a big deal but the issue is at times is he's got his own business...I don't want to be, I feel like I'm a burden on somebody.

IWDD feel both a sense of responsibility toward family members and subsequent guilt in response to not being capable of fulfilling that responsibility. In addition, IWDD feel like

they, themselves, are a burden requiring care. As this passage seems to indicate, Carl appears to be grappling with both dynamics.

**Loss.** Participants who depend on others for assistance with all aspects of daily living experience grief associated with the multiple losses and transitions when caregivers become unavailable to them. Loss is intensified when a primary caregiver dies. Doris suffered traumatic losses when her mother died. She laments “I had to change everything. I lost more than my mom. I lost pets, I lost surroundings that I knew, I lost furniture I knew. I lost everything.” In addition to grieving the loss of her mother, Doris acknowledges, in this quote, many other losses related to transitions that occurred subsequent to her mother’s death.

IWDD’s losses and transitions may be compounded by communication, cognitive and language impairments which may prevent IWDD from constructively expressing their grief. People have misperceptions about IWDD’s capacity to grieve and express their grief. These perceptions create obstacles as IWDD attempt to cope and adjust to such losses. If family and other caregivers assume IWDD do not grieve, their grief is effectively silenced and disenfranchised (Doka, 2002). Doka (2002) explains that disenfranchised grief is grief where the person’s right to grieve is not validated and he specifically identifies that some groups of people (IWDD included) are incorrectly viewed as incapable of grieving. This may be further compounded by failure of concerned others to incorporate the IWDD in preparations for the impending death of a primary caregiver and for contingency planning following that person’s demise.

Grace experienced loss and life transitions following her parents’ deaths. She indicates a lack of autonomy in decision making for her care as she states “My mom and

dad died. Both of them... [And] I came here [the MEC].” Grace was not engaged in the decision making process prior to placement at the MEC. She did not want to leave her family of origin. Grace has a twin sister who has a much milder form of CP. Her sister was able to remain at home with extended family. This further compounded her sense of loss, anger, frustration and lack of autonomy in the decision making process.

Blair experienced fear as she describes her placement at the MEC. The following is an excerpt from Blair’s recollection of her admission to the MEC and the emotions associated with losses she experienced around that time:

There’s a story when I first came here...I didn’t know anyone...and I was scared...and... [I was only] eleven [years old and now I’m] nineteen...and I had um I lost my mother around that time...before that and all of these losses...losses were hard...going through it and accepted it...music helped me cope...and just living.

In addition to the devastating loss of her mother, Blair was dislocated from her family, her siblings, her home, neighborhood and school. She was thrust into an unfamiliar environment without her consult or consent at the very time the comfort of familiar others and home would have assisted her in coping with her grief.

Henry also was placed at the MEC in response to family crisis. His admission to the MEC followed a DYFS (Division of Youth and Family Services, the state child welfare agency) investigation finding of abuse and neglect by his mother who was an alcoholic. He remembers his dramatic, emotional placement at the MEC every time he looks at his father’s photo on the bulletin board in his bedroom:



I mean sure there was that feeling of nothingness when I looked at my father's picture. I had a picture taped to my headboard you know. Him and I in the pool and yeah I cried when I looked at that because yeah you know you've just been snatched out of your family's arms.

Here again, as previously voiced by Doris, Grace and Blair, Henry experiences trauma at his relocation to the MEC following a crisis in his family of origin as he so poignantly articulates in the above excerpt. Clearly admission to a MEC is oftentimes a traumatic, emotionally laden event. Frequently, placement follows an emergency within the family (for example: a sudden death and/or illness of a primary caretaker) which causes placement of an IWDD with very little preparation or input from the individual. Not only are IWDD dealing with grief related to a death, divorce or illness of a family member, they are also thrust into an unfamiliar environment, surrounded by strangers, a new school or program, or unfamiliar routines which further impacts their grief response.

The following interview excerpt illustrates Paul's experience of loss related to the death of his identical twin brother while both were living at the MEC. His twin had the same diagnosis of LND and he recently died due to complications related to the condition. Paul talks about how his relationships with MEC PCAs helped him adjust:

Bonnie: and so that helps? Having good friends? Do you have other good friends here at MEC as well?

Paul: Yeah Tom, Sam, Harry of course and Chuck of course.

Bonnie: Now these last two are PCAs you're talking about. Are they friends as well as PCAs?

Paul: Yeah.

Bonnie: Okay so the relationship is not strictly a worker relationship?

Paul: No they're my coping system.

IWDD also describe loss as a result of staff leaving jobs. Natasha mentions her favorite nurse who left: "Erin, she be a nurse I like; she quit though." The staff tenure at the MEC can be very variable. While some staff stay on for years (as in the case with Paul's special PCAs who are his 'coping system'), for many staff, the MEC is a revolving door. This is the case with many workers who are in minimum wage positions that require a lot of physical and demanding labor.

Relationships build quickly among staff and residents so that even for staff only briefly tenured, they may have built strong emotional bonds with IWDD in their care. Their exit from their jobs strongly impacts the IWDD they leave behind. While it may be intuitive to think that such frequent departures might desensitize the population from developing such strong bonds, that does not appear to be the case.

The depth of relationship among certain staff and participants really depends on the personality of the caregiver so that someone who has only been employed briefly may greatly impact some residents on their departure. This loss becomes exacerbated when well-meaning staff, volunteers, and interns exchange Facebook or email addresses and offer to keep in contact after their departure. This only prolongs the adjustment process as invariably these staff end up ignoring those messages and emails from IWDD, which further exacerbates the sense of loss and rejection that participants feel.

The above quotations indicate that loss is experienced on various levels. There are more typical types of losses such as when people they are close to die. In addition, IWDD experience losses that are tied to their disability such as the various transitions that

are a result of relocating to a MEC facility. These include the loss of surroundings, neighbors, routines. Loss of control and minimized opportunities for self-determination are other factors to be considered here as well. Many participants are not involved in the decision making process of determining where they would go following the death of a primary caregiver; in effect, institutionalization was thrust upon them with very little preparation or understanding. Further, disenfranchised losses are experienced when staff leave their jobs. In addition to feelings of rejection, guilt, and loss in connection to relationships with known others, anger surfaces as another commonly experienced emotion.

**Anger.** Anger is defined as an emotion resulting from a perceived loss which is deemed to be unfair (Barclay, Skarlicki, & Pugh, 2005). This loss becomes blame directed at another perceived willful agent. This concept is illustrated as Tanya expresses her rage about needing to ask others for help: “Sometimes you don’t want to ask fucking people for help. It’s frustrating. You want to blame other people. You feel guilty.” Here, Tanya expresses her understanding that while she is not responsible for her condition, she still retains a sense of guilt for being angry. Her angry admonition fits with the previous definition of anger; blame directed at another willful agent, but for Tanya, that agent is unidentified, hence, she feels guilt at wanting to administer that blame towards others.

Being apart from family and friends invokes a sense of separation and rejection from known others, while stigma and alienation may exacerbate feelings of anger in relation to unknown others. Hence, anger is seen at both levels of extra-personal responses i.e. with regards to ‘known’ and ‘unknown’ others. When directed at ‘known others,’ anger is an undesirable personal trait which must be controlled and modified as

the following quotes suggest. Sofia describes her anger and how she expressed it in a physical and verbally hostile manner:

I used to punch walls and push people away and snap at people. I try not to do that as much anymore because I've seen people in my family who have endured physical violence and I don't want to be that person. So I'm trying to change those traits in my family and I'm trying to change that within myself.

Shannah types out on her voice communicator "WHEN I GET REALLY MAD [at father] I'M NOT SO GOOD."

Participants seem to have an understanding that their familiar others are not responsible for their condition. The IWDD may create justifications for their relatives' / friends' behaviors. When anger is directed at these known others, feelings of guilt and a need to manage one's anger surfaces, as Sofia indicates above. Such anger may also create distance from the very family and friends the IWDD count on to accept and care for them. IWDD strive to gain understanding about the various barriers which prevent the desired degree of interaction with family and friends outside the MEC community.

**Barriers.** Barriers contribute to feelings of isolation from 'known others.' Distance, transportation roadblocks, equipment needs, frailty of aging relatives, and medical setbacks all impact participants' ability to be a consistent part of their family's lives. This greatly impacts their overall adjustment process. Allan has struggled with various medical complications related to his spina bifida. Here, Allan acknowledges the barriers to achieving intimacy with a significant other due his medical/health related issues. He is putting the search for a significant other who can 'handle' his fragile medical condition on hold at present till he becomes more medically stable.

A little bit of a strain because as you know you want to be with the person you know outside of here and you want you know spend more time together and stuff like that. So yeah I've been in relationships where you know kind of put a strain on it ...Right now not looking to be in a relationship if it happens it happens but I would rather medically be more healthy healthier...So when I get a girl and she likes me, my personality and everything else about me and then the whole wheelchair comes into play. At first it's like oh I think I can handle it and then oh no I can't handle it. With me being in a relationship it's not easy... (because) I can't be there at night you know just to lay in bed with you.

Distance is another barrier that known others have to navigate in order to keep in contact with the IWDD who resides in the MEC or at a group home. Due to the specialized nature of care provided at the MEC, many participants relocate from all over the state to live at the MEC. This often results in their being far from their families of origin. This barrier also encompasses transportation, financial and time-related issues as the following exchange with Carl illustrates:

Carl: um well now uh my mother lives in Bergen County she lives up in in Ridgefield Park up by Paramus up there.

Bonnie: That's a bit of a ride.

Carl: and my sister lives up up there too up in ah Dumont...In Paramus.

Bonnie: Are they able to get down here to see you?

Carl: My mother doesn't drive anymore cuz she's uh has some ailments.

Sofia relates her difficulty being apart from her family: "Cause I've been through a lot of crap within the past few years being unhappy living here because I'm not with my family. It's hard because I've always been around family."

Participants strive to understand the reasons why their families and close connections fail to live up to their expectations about maintaining contact. They subsequently feel guilt related to their frustration and anger at their situation. While Carl expresses his understanding of his family's struggles, he still feels excluded from their lives and simultaneously guilty that he cannot lessen their burdens. Sophia, Allen and Henry also speak of their frustration at being separated from family; yet they also understand that it may be in the best interests of all to be apart from their families.

Participants are part of the MEC community, as evidenced by their MEC family quotes, and they seldom feel ostracized WITHIN their community. However, the outside world community has the power to both value and hurt. While manifesting understanding and developing rationales to excuse the separation from family, participants appear to feel a sense of righteous indignation at perceived ostracism and exclusion experienced in relation to unknown others- a topic which will be explored in the next subsection.

### **Response in Relation to Extra-personal Experiences (unknown others)**

Unknown extra-personal relationships have, in general, a very different impact on participants. All of the participants acknowledge enjoying participation in community activities, but many articulate concerns about how others perceive them. Negative interactions profoundly impact their self-concept, possibly contributing to other negative impacts on health and well-being. Such negative impacts may include problems with behavior regulation; IWDD are more likely to behave aggressively (Buckley et al., 2004; Twenge, Baumeister, Tice, & Stucke, 2001), less likely to behave in prosocial ways such as manifesting consideration and altruism towards others (Twenge, Baumeister, DeWall,

Ciarocco, & Bartels, 2007), and may show increased impairments in cognitive functioning (Baumeister, Twenge, & Nuss, 2002). In addition, IWDD tend to engage in self-injurious behaviors to a higher degree compared to non-ostracized others (Twenge et al., 2002). Hence, the task of inclusion vs ostracism is a crucial challenge to navigate for persons with multiple and visible disabilities.

Darling (2003) developed a typology to account for the experiences of individuals with disability and found that there were several recurrent modes of adaptation: altruism, normalization, crusadership and resignation. This typology captures emotional and behavioral elements involved in adaption. In Response I will explore those related to the emotional aspects of coping and adjustment as reflected in the data from this study and will save exploration of the behavioral aspects for the next chapter (6, Reconciliation). Here, many IWDD express a need to have others see them as normal in order for them to feel normal. Moreover, achieving a sense of being valued by others facilitates the development of positive feelings about themselves. Under the axial code of Inclusion, ‘feeling normal’ and ‘feeling valued’ seem crucial in achieving a sense of well-being.

### Inclusion

OPEN CODE	Example Statement
Feeling normal	I FEEL N-O-R NORMAL.
Feeling valued	That people appreciate what I do.

**Feeling normal.** Jaleel recognizes that known others see him differently than those who are strangers in the community: “Other people, it’s not maybe like, well people who work with me know me and know I’m a normal person. People [who] don’t know me outside [see me as being different].” Other quotes indicate a similar sense that being

regarded as “normal” feels good: “To get people to realize we are real people first,” “[I feel] good, like a regular person,” and “it opens up their eyes that we’re just like normal people.” These participants’ quotes suggest that they recognize the importance of having others see them as normal people. The subsequent impact of being seen as normal by others makes IWDD feel better about themselves. These quotes reflect the importance of being seen as normal and subsequently feeling normal as they seek inclusion in the greater social environment.

Richman and Leary (2009) propose a multi-motive model that defines people’s responses to perceived rejection by others. They suggest that there is a strong association between one’s self-esteem and one’s sense of social acceptability. In Recognition, ‘how others see’ me was discussed in a cognitive vein i.e. in relation to participants’ thoughts about how others see them. Here, ‘feeling normal’ is related to the emotional level; when IWDD are perceived as normal by others, this induces a sense of feeling normal. It implies a sense of belongingness of IWDD within a social context.

**Feeling valued.** Having others appreciate them enhances participants’ self-concept. Several artists (the IWDD who work with arts facilitators) in the arts access program acknowledge this beneficial feeling as a result of producing art. Sofia refers to her ballet performances: “I got a standing ovation and it was pretty great.” Maury attests to how it feels to have his artwork on display: “The paintings when they put them out on display...they don’t really say well this person is in a wheelchair and did this... [it makes me feel] good, like a regular person.” As seen in both of these quotes, participants refer to positive feelings associated with being appreciated for their artistic contributions, especially by ‘unknown others.’ This process has a normalizing effect and appears to be



an important element in achieving a sense of well-being for these participants. Hence, maintaining an identity of ‘myself as an artist’ is an important way the participants gained positive recognition and appears to be protective.

Alternatively, when inclusion is not achieved, participants feel ostracized. There is an extensive body of literature examining the negative consequences of the effects of ostracism and rejection (Buckley et al., 2004; Bayram et al., 2012; DeWall et al., 2009; DeWall et al., 2011; Twenge et al., 2002). This literature consistently indicates that ostracism, rejection and discrimination profoundly impact an individual’s self-esteem, emotional health and well-being (Richmond & Leary, 2009).

Social exclusionary processes are described in the literature as leading to a sense of losing one’s sense of ‘belonging,’ leading to subsequent susceptibility to further oppressive types of reactions on the part of society i.e. elevating risk of exploitation and marginalization (Susinos, 2007). IWDD are confronted with barriers outside the MEC on a daily basis that further exacerbate a sense of being excluded and rejected. These barriers include: communication barriers, access barriers, and medically related obstacles. Participants report experiencing alienation, anger at feeling alienated, and a sense of resignation to ostracism consistent with the literature on disability-based prejudice (Park, Faulkner, & Schaller, 2003).

Park, et. al. (2003) describe “disease-avoidance processes” as the evolutionary reason for responses such as disgust, anxiety and negative attitudes as mechanisms to avoid contagion – but this means these responses can be applied to many perceived anomalies (such as physical disabilities). While perhaps adaptive in an evolutionary context, it is suggested that this reaction has become over-activated and can be triggered

by non-contagious, but visually perceived, anomalies. It is clear how activation of disgust, anxiety and negative attitudes can contribute to exclusionary actions towards IWDD, which in turn lead the IWDD to feel anger at the sense of rejection they experience. Park, et al.'s thesis may explain the disgust some members of the public display towards IWDD, but for IWDD, the sense of ostracism is what remains.

### Ostracism

OPEN CODE	Example Statement
Anger	You know that bugged me. It made me mad.
Misperceptions:	
-being contagious	There's this one woman in the gallery of New Brunswick she thinks that I'm gonna get her sick you know because I'm in a wheelchair...
-being stupid	I'm in a wheelchair, not stupid.
-being an alien	That we're weird aliens and we're not human you know.

**Anger.** As previously mentioned, the Response of Anger is different when examined in the context of unknown others. With known others, participants appear to recognize their need to modify their attributions of perceived loss; with unknown others, they perceive that the onus is on people in the community to modify their perceptions of IWDD with visible disabilities.

A great deal of anger is expressed by participants towards others in the community for perceived stigma and negative stereotypes which they feel are being applied to them by unknown others. Participants appreciate the opportunity to speak with others in community settings and seem to intuitively understand that by achieving a personal degree of familiarity, these social barriers may be broken down. When this type of communication is prevented from happening, much anger and frustration is elicited.

Sofia admits to having an explosive temper; she expresses her anger as she relates a story about encountering a child and the child's guardian in a mall:

This one little boy asked me why I was in a wheelchair and the mother or the grandmother, I don't know who it was, grabs the child on the arm ...kicks him and he falls on the floor...and I approach the woman. I tapped her on the shoulder 'excuse me that wasn't necessary, I'd rather him ask me than be ignorant like you.' And then she grabs him again and kicks him again. I wanted to slap the crap out of her. Who tells a little boy not to ask her that and then kicks him on the tush to where he falls on the floor?

Likewise, Henry (the ballpark vendor) indicates awareness of these invisible social barriers as he relates a story that occurred during a shift last summer:

I have a ton of anger at people in society, not at the people asking the questions, but the people who get mad at other people for asking the questions. When I had first worked at the ball park, I get good questions from the little kids – I'd just say I was born like this. Some mothers would say 'don't ask him that' or kicking them on the butt and not becoming aware of what a disability is. The walls are very easy to come down. It's just whether the person you're interacting with wants those walls to come down.

In both of the above excerpts, Sofia and Henry are open to educating unknown others about their disabilities. They express anger and outrage when those individuals are prevented from asking questions by guardians who maintain fear and misperceptions and prevent their children from gaining knowledge and familiarity about the population. They recognize that when others maintain ignorance towards IWDD, this serves to

perpetuate their misperceptions. Carl also expresses anger and frustration at his perception of ostracism from others as he relates a story about others' reactions when he goes out to eat in a restaurant:

You know that bugged me and it even bugs me even now today. There's times I've gone out with friends of mine or people from the group home and we go out to eat and they [other patrons in the restaurant] don't like people [like us] coming in and they ask to be moved. And they would move them, which was fine and the person or people I was with, I turned around and said loud enough so the person could hear wherever he is, 'come on... come on what do you want us to do here you know.'

Here, an interesting phenomenon becomes manifested. It appears that the understandable anger of IWDD at being ostracized then works to have those unknown others (who are ostracizing them) feel angry themselves, thereby creating a vicious cycle of rejection and anger.

**Misperceptions.** Other stigmatizing misperceptions seem to exist as the participants report their sense that they are perceived by others as: "being dumb," "being contagious," "being an alien," and "being weird." Hence, the sense IWDD have of being dehumanized shows in these quotes. Dehumanization is a commonly used stereotyping phenomenon associated with stigma (Goffman, 1963).

Ivan is particularly prone to incurring misperceptions on the part of unknown others because he is non-verbal. He is keenly aware of others' negative perceptions, as described above, when he viewed others as 'stupid' for viewing him only as "the chair." Research suggests that social rejection promotes low self-esteem, along with higher rates

of mental and physical illness (Baumeister et al., 2007) and diminished overall quality of life (Buljevac, Majdak, & Leutar, 2012). Participants react to these misperceptions with anger. They create and utilize strategies to break down exclusionary barriers, which will be explored further in Reconciliation (the behavioral enactment of Recognition and Response).

In summary, the second overarching theme of Response describes the emotional reactions of participants to coping with multiple and visible disabilities. At the intrapersonal level, the IWDD in this study develop resiliency strategies which are characterized by motivation and goal setting. In addition, some adopt a defiant attitude to move on with their lives and achieve their goals despite their disabilities. For those who fail to maintain realistic objectives, some may experience disappointment, pain, and despair which lead to depression, and for a few, suicidal ideations.

At the extra-personal level, participants experience belonging and fitting in with known others, along with disappointment, rejection, anger and loss when barriers prevent them from being with their family and friends. At the unknown extra-personal level, most sense ostracism and rejection from the community at large. Participants seek to break down social barriers by engaging in interpersonal conversations with unknown others and feel frustrated, disappointed and angry when prohibited from doing so. These projections (ostracism by 'unknown others' is followed by anger which then yield more rejection of the anger) becomes a potential vicious circle, while the chance to be known (i.e. educate children about their disability) creates bridges of understanding and pathways to acceptance.

## Chapter 6. Reconciliation

Participants' *Responses* lead to either resiliency or despair in their feelings about their relationships with 'known' and 'unknown' others. In this section I discuss how participants' *Responses* set the stage for their behavioral responses to those feelings. These behaviors include maintaining interpersonal relationships, enacting valued identities (perceived higher status e.g. 'being an artist,' 'being a mentor'), and gaining control/self-determination and agency in pursuing goals. In the optimal outcome of Reconciliation, participants work toward integration and acceptance into social networks; if this is not successful, they experience rejection and isolation.

Specifically, Reconciliation is the behavioral domain of the three overarching processes. Reconciliation is characterized by the task of enacting *Acceptance by self and by others* i.e. integration into society- the core category (see Chapter 4), or not accomplishing that goal. Like all humans, IWDD (individuals with developmental disabilities) want to be accepted in their social environments. They often have challenges in this quest for acceptance due to the greater likelihood of stigmatization and devaluation. The participants in this study may experience integration and a sense of acceptance which seems to positively impact cognitive self-appraisals (thus, enhancing self-acceptance) and ultimately may positively impact self-concept. All of the 'being' statements are incorporated under this category i.e. 'being an artist,' 'being an athlete,' 'being productive,' etc. It appears as though participants seek to be accepted by others by enacting social identities through engaging in socially valued activities.

The tasks for Reconciliation operate at all three levels i.e. intrapersonal (self), extra-personal (known – familiar others) and extra-personal (unknown – in the larger

community) as do the other two thematic categories (i.e. Recognition and Response). At the intrapersonal level, the behavioral reaction consists of IWDD enacting a socially valued identity and reconciling their ‘disability identity.’ The intrapersonal level is a subcategory I have labeled ‘self-acceptance.’ It is further described by an axial code: Enacting Valued Identities. While participants enact many different identities depending on the particular social context, I focus on two particularly powerful identities as examples, ‘Being an artist’ and ‘Enacting one’s disability identity.’ By owning and enacting one’s ‘disability identity,’ IWDD gain a sense of control/self-determination over their own life circumstances. They move from a sense of powerlessness to one of strength, control and esteem (i.e. impact on self-concept).

### **Self-Acceptance**

#### **Enacting Valued Identities**

OPEN CODE	Example Statement
Being an artist	I’m a writer, I’m a dancer, I’m a choreographer.
- Self-expression	I let my feelings out through my art.
-Being free	Freedom... I can say anything, do anything.
-Being productive	Making money. Things I work hard on, things I sold.
-Gaining control	I can express myself any way I want through my art, unlike the rest of my life which is so controlled.
Enacting a disability identity	It’s a part of me, I wouldn’t change it.
-Being empowered	It’s very empowering for me ...I like that.
-Being in control	Being in control.

**Being an artist: self-expression.** ‘Being creative’ and ‘making art’ was coded fifty-eight times in addition to participants’ involvement in specific arts such as: ‘being a painter,’ ‘being a poet,’ or ‘being a dancer.’ Participants use art for self-expression, coping and as a hobby that is fun to do. Using art as a vehicle for self-expression was coded twenty-seven times throughout the transcriptions. Jaleel reflects on his use of art for coping; “If I didn’t have that [art] I would be on medicine going crazy.” His quote suggests that if he did not have art he would not be able to cope with his psychological distress. He goes on to elucidate the feelings he expresses in his art “Anything, frustration or happy thoughts or unhappy thoughts or depressed thoughts or any thought that comes to mind I just slap into a painting.” Frank explains what his artistic expression is like for him: “Yeah because even though I physically have the disability, it’s a way to get out, it’s a way that I can get out from the mundaneness.”

**Being an artist: being free.** “Freedom” is frequently articulated as a benefit of producing art for participants. For individuals who have expressive language difficulties and are dependent on others for assistance with all aspects of their daily lives, art provides them with a sense of control, a medium for self-expression as well as an emotional release from the confinement of their lives. Grace describes the freedom, independence and escape from others’ judgment she feels when she creates art: “Like I’m free from my life for a while. I get to be free like but nobody could tell me how to do it nobody and no one could judge me.” Shannah types her response to my question asking what it was like for her the first time she went to the facilitated arts program: “ IT WAS F-R-E-E-R FREER...IT WAS FREER I WAS NOT LOCKED IN MYSELF NO MORE.”



Paul struggles with multiple medical difficulties and physical limitations. He is in safeguarding equipment due to his tendency towards self-injurious behaviors that are characteristic of his diagnosis. Safeguarding equipment includes wrist, arm and leg straps binding him to his wheelchair. The straps prevent him from hurting himself or others. As a result, he is unable to operate a motorized wheelchair or to self-propel a manual chair. He is dependent on others for feeding him his meals, moving him to various locations, and all activities of daily living. Here, he describes the freedom he experiences being able to control and manipulate his environment through the facilitated art process: “I am free because I have the only say in what happens in my art. It relaxes me and allows me to get my frustrations out.”

Grace describes what performing in a facilitated dance program is like for her: “It’s liberating being that I can’t get up out of my chair and dance myself.” Grace choreographs and performs in her own dance pieces. She directs the dance facilitators in their movements and in how they move her about the stage. She chooses everything related to the performance including the music, the dance moves and the costumes. The entire piece is her vision. In the above quote, she recognizes her inability to independently experience her dance vision but through the facilitated arts program, she is able to freely express herself through directing others as well as participating in the dance herself (with others’ assistance).

**Being an artist: being productive.** In addition to experiencing freedom, enacting an artist identity allows participants to be productive. Participants produce artwork which is displayed for the MEC (medical and educational center) community as well as in public arenas. There is an online website that can be accessed by the public at large.

Works of art are sold for hundreds of dollars from which the participants receive a percentage (after the gallery fees are deducted). This provides participants with a sense of accomplishment, as well as monetary gains.

Grace recalls what she likes about completing an art project: “because at the end of it, you have something you accomplished.” Jaleel has achieved positive recognition for creating art. He describes what he enjoys about the process “I sold two of them. I got an award for it.” He goes on to reflect: “I worked really hard on it. I took my idea and ran with it. I really loved it. Other people took it and put it in their art gallery.” Clearly he is describing a sense of accomplishment at having completed a project that received outside accolades as well as a project that reflected his own personal vision.

Tanya discloses how she uses her artistic ability to give back to others and gain some autonomy, “This one I actually donated to a memory of someone that passed away, to my friend’s father who passed away of diabetes in memory of him. I gave it to her [and told her] this is for your father.” Several participants use art to memorialize others who died. Additionally, they honor those they feel grateful to as Oscar relates regarding a painting made in homage of a valued PCA (personal care assistant).

Bonnie: Is there any painting that you’d like to talk about?

Oscar: Yes. That one.

Bonnie: This one you want to talk about? Oh and this one’s called Tristan’s Heart of Gold and Tristan’s one of the PCAs here right?

Oscar: Yes.

Bonnie: And so tell me about this painting. Tristan is a special person to you?

Oscar: Yes.

Bonnie: That seems to be a theme you have in some of your paintings that you have somebody who's special to you that you paint about?

Oscar: Yes.

Bonnie: Yeah? Can you tell me about this painting? What reminds you of Tristan?

Oscar: His heart.

For those who are dependent on others for assistance with all aspects of their daily needs, the ability to produce an admired piece of art might provide them with a sense of autonomy in being able to give back to others.

**Being an artist: gaining autonomy and control.** An additional benefit of creating art within the context of a facilitated arts program is the sense of control that is derived from participants guiding the artistic process. Participants value the freedom, control and sense of empowerment they experience in directing the facilitators in the creation of their vision. As Grace articulates "It's very empowering for me. It's like what I say, they do, and I like that." Tanya reflects "Nobody could tell me how to do it," and finally Doris states "It's good cause they're doing exactly what I'm saying them to do." Having the opportunity to direct and control others' actions is very freeing and empowering and clearly of benefit to participants' sense of well-being.

Creating art has been used to combat stigma in communities of those with psychiatric diagnoses (Thomashoff, Kopytin, & Sukhanova, 2009), to facilitate life quality (Svensk et al., 2009; Sandel, Judge, Landry, Faria, Ouellette, & Majczak, 2005), to provide health benefits in those with chronic illness (Broderick, Junghaenel, & Schwartz, 2005) and to enhance psychological well-being (Regev & Guttman, 2005). Doris has a tendency towards depression. She reports that making art has helped her deal

with her depression. She states, “It made me feel better because it brings me joy into my life.” Grace reflects on how participating in the facilitated arts program has enhanced her sense of well-being: “Without [the facilitated arts program] I don’t know what I would do because I would walk away from myself before. I [wasn’t] as happy as I wanted to be before I started art.” Jaleel states “I feel happy when I paint.” These statements suggest that creating art may have a positive effect for participants on their emotional state and overall sense of well-being.

Sulewski, et.al. (2012) investigated the intersection of the artists’ identity with the disability identity for those individuals with disabilities who produce art. Their findings suggest a powerful impact of art on the development of identity formation in individuals with disability. They suggest that for some artists with disability, making art facilitates movement towards their acquisition of a more self-perceived normalized identity. Achieving a normalized identity fits with many of the quotes by participants referenced in Recognition and has implications with regards to IWDD in this sample integrating in the wider community. The next code under the axial code of enacting valued identities is how participants enacted and took ownership of their ‘disability identity.’

**Enacting the ‘disability identity.’** An overarching research question for this study is how individuals with disability make meaning of their identities? For these participants, the ‘disability identity’ emerges as a prominent self-perception encapsulating most of their other roles and attributes both positive and negative. Contrary to the experiences of those who acquire disability later in life, IWDD have no experience of life without disability. They begin to recognize their differentness from others as they gain social awareness of themselves in relation to others. As they become

aware of themselves as a person with disabilities, this identity becomes an important aspect of their self-concept. Data derived from the HICLAS (hierarchical class analysis) structural models provide further support for this finding (to be discussed further in the ‘HICLAS’ analysis section) whereby the disability identity surfaces high up in each individuals’ identity structure and is associated with a broad array of positive and negative features/attributes.

The disability identity is pervasive. Justifications and rationalizations were used to temper the negative aspects of having a lifelong, visible disability. To further counterbalance the negative perceptions that disability incurs, many participants engage in a process of embracing their disability identity. It is an important part of who they are. They have no life experience of being without a disability. In addition, they understand they are powerless to change this aspect of themselves and some may not want to change this aspect of themselves even if it were possible. Sofia reflects on whether she would change her condition if she could:

You know, if they had a magic pill or some magic wand or something to make me walk what’s the point? As long as I accept it myself that’s all that matters. Maybe if the person wasn’t born with a disability and became disabled, maybe they would want to change it but me, since I’ve always been disabled if they had a pill or something for me to walk, I probably wouldn’t even take it because it’s not going to change anything it’s not going to change who I am as a person.

Here she indicates understanding that since she’s always had her disability, disability has become an integral component in the way she sees herself. She indicates that someone with acquired disability may feel differently about having their disabling condition.

Literature corroborates this rationale. People with developmental disabilities tend to maintain increased positive self-perceptions compared to those with disability acquired later in life (Bogart, 2014; Darling, 2003). Tanya replies to the same question: “No I wouldn’t change anything about myself” and Carl states his feelings about having disability: “I don’t have a problem with it.” He further reflects on having disability:

I wouldn’t wish this on anybody but I will tell you that if anybody had to have this, had to have disability, I’m not gonna sit here and say I wish [I had] it or if I had my choice I would pick it. But I’m glad that I got it.

In addition to accepting their disability identity, identifying with the disability community at large paves the way towards IWDD gaining empowerment and agency in enacting social justice initiatives (as seen in minority perspectives). Henry articulates his self-perception as an advocate for others. Living a large portion of his life in a facility with others with significant disabilities provides incentive for Henry to take up an advocacy mantle. Many others at the MEC are unable to verbalize their feelings. Henry is extremely articulate and recognizes this as a strength for himself which he can use to assist his MEC peers. He attaches many positive attributes to his ability to advocate for others:

Well the first thing I would say is, I think I’m a strong leader um I’m always one not to follow. I love to lead. When I find something is wrong, I’m very boisterous about it and I consider myself to be kind of a voice of the voiceless. I know it sounds kind of like I have a God complex but that’s really not it. I just like standing up for people when they can’t stand up for themselves.

As mentioned in Response, Darling (2003) created a typology accounting for various types of disability identities IWDD utilize in adapting to their disability. These identities are promoted through disability culture and the disability rights movements; emphasis is placed on the drive to access a sense of normalization and affirmation by affiliating with others who have disability. The variety of identities maintained by IWDD as elucidated in Darling's typology is proposed to have implications for understanding the variable disability landscape. Darling suggests that those with congenital disability may be more likely to identify with a disability identity than those who acquire disability later in life. Adopting a salient disability identity has been purported to assist individuals in adapting to disability (Dunn & Burcaw, 2013) by creating an 'ingroup' network of associates and a sense of belongingness.

Alternatively, when *self-acceptance* is not achieved, what I term negation of their disability identity comes into play in participants' overall adjustment processes. When IWDD in this sample do not develop valued identities which they then enact in various settings, they suffer consequences of emotional distress, regret missed opportunities, and negate their disability identity which I term 'resignation'. This can be a pivotal event which may move someone out of emotional equilibrium. Specifically, I posit that negating a part of oneself that is integral to one's overall sense of self will yield diminished sense of life quality and well-being. It is important to note that these states of being are fluid and are seen in terms of the contextual environments within which participants navigate.

### **Negation of the Disability Identity**

#### **Resignation**

OPEN CODE	Example Statement
Lack of control/dependence on others (Apathy/stagnation)	I cannot move around so I have to be dependent on other people. At times I feel um stagnant. I felt so many times that I've been stuck.
Missing out/missed opportunities	Yeah I do feel I missed a lot growing up. I will never have a baby. I missed a lot.
De-emphasizing disability identity	It's a part of me but it's not all of me.

**Lack of control.** Understandably, one of the greatest difficulties encountered by participants is a perceived lack of control over themselves and their environments. Participants in this sample combat their lack of control by adopting positive coping mechanisms such as positive thinking as well as redirecting their focus towards areas where they do have control such as participation in a facilitated arts program. However, even those with adaptive coping skills reflect on their limitations and need for assistance with all activities throughout their lives. Blair, Doris and Joe reflect on needing to depend on others. First Blair observes “You have limitations on what you can do. If you’re a very independent person, it’s tough to rely on other people. It’s difficult [PCAs are] not always available all the time.” Doris mentions her lack of personal time to herself: “You’re not really all that free to have all that much time to yourself.” Joe elaborates on his sense of frustration at being dependent on others:

There’s times when I need help you know. It’s frustrating sometimes cuz like I say you always have to depend on somebody. It doesn’t happen all the time. It’s just that when you really want to try to do something that you know you can’t do but you still try to do it, I think when that happens I get all upset [and] frustrated.



Jaleel is a young man who grapples with the reality that he is unable to exhibit sufficient competency over his own affairs. He is assigned a guardian through the Division of Developmental Disabilities (the state organization overseeing IWDD's allocations, programs and support services) to make decisions on legal, financial and medical matters. Jaleel is an articulate young man with neurological processing disorders in addition to spastic quadriplegia secondary to cerebral palsy (CP). His family is unsupportive and uninvolved in his life. He is unable to read, write or do math. Competency testing has indicated his need for a guardian to make decisions on his behalf. Jaleel has unsuccessfully attempted to challenge this decision by the state's court system. He laments in response to a question on whether he would change anything about himself if he could: "And not to have to ask nobody if I could do it. Not have to get approval [from a guardian]."

Participants regret the need to have to wait on others' time schedules, and become frustrated and angry at this interruption in the flow of their lives. As Doris points out "you have to wait for help so I think that's the worst aspect of it." Allan reflects on his many years of medical and physical setbacks:

At times it gets very hard you know. I've been going through all of this the surgeries, and you know bed rest, just difficult things so I had to adjust to it. [I came to] learn that I just can't go do what I want to do. I have to be very patient. Carl, who is middle-aged, thinks on his declining abilities: "My ability to do things on my own has decreased and sometimes that bugs me." Carl recognizes that the abilities he did have are now on the decline, increasing his dependency on others.

It is evident that having such a degree of dependency can negatively impact a person's autonomy in accomplishing what s/he wants to do during the course of their day. Participants speak about their anger, regret and lack of agency in having to be reliant on others to such a significant extent. Participants acknowledge their sense of missing out on opportunities in relation to their disabilities. Hence *Missing out* becomes a second coded response under this axial code of resignation.

**Missing out.** Participants articulate regret and loss as they speak of missed opportunities related to having disability. Jaleel who recently graduated from the specialized high school program states:

I wish I was able to go to regular high school and I had to wait till I became twenty-one to graduate. I would like so many things to change in my life. I would like to have a job, I would like to have a girlfriend, I would like to go to college.

Participants maintain goals and dreams that oftentimes cannot be realized due to their need for physical supports (as discussed in *Loss of future dreams* in Response). When participants are unable to behaviorally participate in various desired situations due to their disabilities, they report a sense of missing out and being dependent which then exacerbate their negative feelings about having disabilities.

Hence, for some IWDD, the disability identity (while still an integral component) becomes a negative part of their self-concept. Rather than embracing having disability, some seek to de-emphasize it and prefer to be perceived by themselves (and others) as non-disabled. While superficially this may seem to have adaptive value associated with rejection of a negatively perceived identity; for IWDD, rejection of their disability

identity may lead to identity confusion, regret and disappointment. Some participants lament ‘how much more they could be doing with their life’ if they did not have their disabilities, Allan states:

But mentally I feel like that you know I can be doing so much more with my life. I guess in certain aspects there’s a lot I want to be doing but right now that I can’t cuz you know medically [I’m unable to].

Carl echoes this sentiment as he regrets not being able to be more active: “At times I feel stagnant. I would like to be a little bit more active at times.” Jaleel pines for the other activities, relationships and future goals he feels inhibited in accomplishing due to his disabilities. In addition, having to wait on others is also an issue for him:

Yeah I used to hate it; personally I would rather be home with the family, or with a girlfriend, or living on my own, having a job, going to school. Getting out of here [the MEC], not having to wait for a van.

In concert with Jaleel’s sense of frustration at feeling unable to enact his dreams of going to school and eventually moving out of the MEC, several others speak of long missed opportunities. These opportunities include: going to school, getting married, having children or having a high-powered job. Caregivers, instructors and educators tend to prime IWDD for failure with the erroneous notion that they can achieve whatever they want if they work for it hard enough. This is a foolhardy promise which cannot be achieved by anyone, even those without disabilities. When participants realize they have limitations even more significant than ‘normal’ people in achieving lofty objectives, they experience loss, frustration and anger (as discussed in Response). These feelings lead to inertia resulting in participants being unproductive and limiting motivation for enacting

realistic expectations of themselves and others. In this regard, participants then seek to de-emphasize their disability identity.

**De-emphasizing disability identity.** Contrary to Darlings' framework, there may be value in emphasizing alternate identities without any attached stigma in enhancing self-concept by increasing complexity of self-concept (Wang & Dovidio, 2011). Participants appear to utilize both strategies in coping with visible and multiple disabilities. They may embrace empowering aspects of their disability identities or emphasize other identities within their self-concepts that are associated with positive features and, in effect, de-emphasizing less desirable identities.

Maury responds to a question on whether disability is an important aspect of how he sees himself: "I don't like being disabled so I would say no I guess you could consider the disability to be a negative. I don't like being disabled really." Maury chooses not to focus on himself as 'one who is disabled.' Several other participants also neglect their disability identity through identification with others who are non-disabled. IWDD may reject opportunities to form friendships and romantic relationships with others who have disabilities and prefer to be in the company of 'normal' people, defined here as people without disabilities. Further, they may seek to form affiliations with others who are non-disabled through participation in various venues such as volunteering, religious events or through employment. While this coping strategy may be perceived by disability crusaders as a rejection of their disability identity, there may be positive aspects to promoting other identities within self-concept associated with activities characterized by IWDD with positive features. This will be further explored in the next section on *Reconciliation in reaction to known others.*

## Reconciliation in Reaction to Known Others

At the extra-personal levels, there are separate tasks describing behavioral reconciliation to familiar (known others) and unfamiliar (unknown others) in the community at large. The task at the known other level consists of maintaining interpersonal relationships with familiar others such as family, friends/peers, ‘MEC family’ and other caregivers. Specifically, participants strive to actively engage in valued relationships versus being separated from their family and friends. I have labeled the second subcategory under the theme of Reconciliation: Acceptance/Intimacy vs Isolation.

There are three themes under the subcategory of Acceptance (known others). The first theme is with respect to close personal relationships with friends and family and is titled: Intimacy. The second theme is Sexuality. The third relates to Romantic relationships. All of the participants strive to develop close intimate and nurturing relationships with others. As previously mentioned, “Being with my family and friends” was coded over one hundred times throughout the transcriptions. Maintaining close personal connections, having a ‘special bond,’ staying connected with those who are separated due to distance, financial and transportation barriers have substantial impact on participants’ sense of life quality.

### Intimacy

OPEN CODE	Example Statement
Being with my family/friends	[Being with] and loving myself, my family and the people around me who love me.
Special bond	Me and Randi [my RN] we’ve always had that special bond.
Barriers	I want to be with my family and friends and a lot of times I can’t do that because of medically I can’t right now.

Using technology/  
staying  
connected      Cuz we're on skype sometimes 24 hours a day you know we're talking.

**Being with my family and friends.** Participants related over and over that one of the most positive aspects of their lives was being with family and friends. Human beings are socially motivated creatures and seek to be involved with others in social situations. Families are where the first relationships take place for most people. The majority of participants lived with their families of origin for many years prior to moving to the MEC, group home, or supervised apartment. For some, this transition was traumatic and the separation brought grief and loss (as mentioned in Response). Maintaining contact and nurturing those relationships continued to be important aspects of participants' lives long after their relocation to the MEC. Participants value those connections and get angry and frustrated when families do not meet their expectations of staying connected with them on a regular basis.

Blair voices her need to be around people who are dear to her. She states "I want to be around people I love and cherish and I know." Jaleel echoes this desire along with some frustration at family who often disappoint him: "I love talking to my family but sometimes they can be idiots. Sometimes they can be not there [while] I get to see my friends each and every day at [MEC]." Frank speaks of a long held dream to eventually move in with his father: "I wonder if things will be in place so I can move out with my father."

Relationships with family are crucial in providing the participants with a sense of well-being and acceptance. The next few responses are in relation to an interview question asking participants to complete this sentence: the most important thing to me

is... “My family,” “My mom and my dad too,” “Like love and family and friends not the material stuff like money.” Henry reflects on his deep bond with his father in response to this question:

I’ll say my father and my family. Because you say MEC is a great safety net. I have an almost a foolproof safety net you know. MEC’s safety net is good yes, 99.99% effective, but they do have cracks. My family has come through for me in times of hardship. Me and my father are like best friends.

Tanya continues to reside with her family of origin in her community. She greatly values the love and support she receives from them and her friends as she articulates “Family, my friends, good friends help you move forward in life. [You] get good support from your friends and your family.” In addition, participants articulate their sense of having a ‘special bond’ with certain friends, family members and caregivers. ‘Special bond’ is an emic code that arose in the transcriptions several times over the course of the interviews.

**Special bond.** As indicated in the next couple of quotes, participants consider the special bond they have with certain family members and friends. Henry states “Daniel (a friend) and I have a very strong bond and I mean because we’re best friends. We do have our disagreements about things but we make up afterwards.” Sofia says “I have a great relationship with my sister.” Family presents a strong support group for many participants despite their need to live away from their families.

Perhaps partly in reaction to being separated from families of origin, participants who reside in the MEC develop special bonds with their caregivers. Oftentimes those bonds transcend the boundaries of patient/caregiver relationships. Roger, who is

diagnosed with Lesch-Nyhan Disease (LND), is credited with arranging a romantic match between his PCA and his Adult Services Instructor. Roger set them up on a date and they eventually got married. Roger attended their wedding as a special guest of honor for arranging the match! He derived much pleasure out of being able to give back to his PCA. LND is a difficult diagnosis to live with; likewise, it is challenging to be a care provider for individuals with LND. PCAs have to be specially trained and be of a certain personal character in order to cope with the demands that this challenging diagnosis presents. As a result, the bonds that develop are extremely nuanced and unprecedented in caregiver/patient relationships. This particular scenario serves as a prime example of how special bonds may develop and enhance both IWDD and caregivers' lives.

Alternatively, being separated from family and friends is articulated by participants as a negative aspect of their lives. Various barriers contribute to this separation. These barriers include physical, medical, distance, time and transportation related issues.

**Barriers.** IWDD are institutionalized most often due to the burden of care their condition places on families. Further exacerbating this situation, as IWDD age, they become more difficult to manage due to their size and/or medical fragility. This may decrease the frequency with which IWDD can go on home visits. As Doris reflects "You want to be with your family [but] they can't handle you anymore. I guess that's not only in cerebral palsy that's in a lot of disabilities." Their ability to be with their family and friends on overnight home visits or even day trips becomes compromised. As a result, the frequency of home visits decreases over time. Their burden of care becomes a barrier for engaging in interactions with family and friends outside of the MEC community.



Allan, as previously mentioned, experiences frequent medical setbacks and long durations of bedrest due to wound care issues. Here he reflects on medically induced barriers:

Well I've been through a lot medically where I've been forced to be on bed rest for long periods of time and you know to be able to adjust to it, go with the things I need to do for myself to be able to get better. Sometimes it's very frustrating because I want to be able to be out doing so many things. And you know, being with my family and friends. And a lot of times I can't do that because of medically I can't right now.

In addition to medical barriers preventing participants from leaving the MEC to visit with families and friends in their communities, barriers arise for families in visiting with participants in the MEC. Such barriers consist of financial limitations, time constraints and distance issues: "My family is about an hour away," transportation difficulties: "My mother doesn't drive anymore cuz she's uh has some ailments." In addition, some families are busy with other life circumstances as Jaleel laments about his family's infrequent visits: "Yeah, they're all having kids, having their own lives, having this and that." The preceding excerpt has implications for social barriers in addition to the physical barriers precluding contact with family and friends. Perhaps, some families may not desire the continuity of contact to the extent that participants do. Failure to communicate this or reluctance on the part of participants to pick up on non-verbal cues may result in misappropriating blame for lack of contact on physical barriers.

Family and friends can mediate the achievement of a sense of acceptance for IWDD. Having those close relationships and special bonds are therapeutic and self-

affirming for participants. Alternatively, when barriers get in the way of their ability to have those close contacts, participants experience frustration, anger, disappointment and loss. These emotions contribute to participants' experience of pain/despair (as discussed in Response) and an overall sense of being out of touch with valued others (family and friends) thereby affecting IWDD achieving well-being and life quality. Technological advances enable IWDD to continue those relationships and connections beyond any previously envisioned scope of reference.

**Using technology to stay connected.** Allan is unable to see his friend regularly. He reflects "Yeah but we always talk. She's on Facebook, I'm on Facebook. I got her hooked on Facebook now she's always on Facebook." Henry states "I have a few friends I stay in touch with, we text each other here and there." Skype, cell phones, email, Facebook, Instant Messenger, Twitter and Instagram are all technological methods of communicating and staying in touch with valued others. Using these technologies may mitigate some of the negative aspects of being separated from family and friends.

The next axial code under the subcategory of intimacy with known others involves sexual relationships. Participants were asked about their sexual relationships in the context of understanding what aspects of their lives give them life quality. Sexual relationships as an axial code, is seen here as a separate entity from romantic relationships, which will be discussed as the next axial code under this subcategory. Four sets of open coded responses emerged under this axial code: celibacy, for procreation purposes, for physical pleasure and release, and barriers to sexual expression.

### **Sexual Relationships**

OPEN CODE	Example Statements
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Celibacy	I'm a virgin. Yah I've never had a relationship like that [sexual] nor would I want one.
For procreation	If I'm going to have it [sex] I want the children to go with it.
For physical release	Being horny.
Barriers	I don't have full privacy.

**Celibacy.** Most of the participants report being celibate. Doris (who is fifty-four years old) states “I never had real sexual relations or anything like that.” When asked whether that would be something she would like to have in her life, she responds “When I'm married.” Very few participants indicate a desire for sexual interaction purely for physical release without the relationship component.

Some indicate that they have had sexual experiences but were currently celibate. Maury responds to a question on whether he has a satisfying sexual life: “Um yeah uh not right now but I have yes. I'm okay with the way things are for right now.” These observations are consistent with literature indicating that there is wide variability in sexual activity within populations of IWDD and that actual intercourse is rare (Lofgren-Martenson, 2004). Lack of sexual activity for IWDD is attributed to knowledge deficits due to cognitive impairments of IWDD, staff members' restrictive attitudes towards sexual activity in the population, as well as the need for facilitation by support persons (Mona, 2002; Swango-Wilson, 2008).

**Sex for procreational purposes.** Most of the participants ONLY view sexual activity for the purpose of having children. Intimacy and sexuality are seen as discrete entities with most participants viewing intercourse for procreation purposes. Blair shares “I want to have babies and I want a normal life” in response to the question about whether she would want a sexual relationship in the future. She appears to equate sexual

relations with having children as part of the normal life cycle. She goes on to state that sex for the purpose of having babies is the only time she would consider it and even then, only within the context of marriage.

Grace's boyfriend is Luis. She mostly sees him two times per week at the Adult Day Program. She lives at the MEC, he lives in a group home. They also get to spend time together at special events that the MEC sponsors such as prom night where they sat together at the formal dinner and danced to the D.J. Pictures of Grace and Luis at this year's prom show them smiling and holding hands.

Bonnie: Um how about physically are you able to be physically romantic with Luis?

Grace: Not here yet but in the future I hope to.

Bonnie: What are your hopes?

Grace: To have a kid with him.

Bonnie: Do you want to have a sexual relationship with him?

Grace: Yeah but not right away you know what I mean.

Bonnie: Well I'm not sure that I do can you be a little more specific?

Grace: Like I want to be a mom and a wife to someone.

Bonnie: So those are your hopes for the future?

Grace: Yeah.

This passage indicates that Grace views sexual activity with Luis in connection with achieving the normalizing goal of procreation and becoming a parent within the context of marriage. She did not express a desire to experience sexual intercourse purely for sexual release nor to obtain a greater degree of intimacy with Luis.

**Sex for physical release (“being horny”).** Surprisingly few participants report wanting to have sexual interactions purely for physical release. Henry reflects on having sex with a partner he has no romantic interest in: “Yah I’ve never had a relationship like that, friends with benefits, nor would I want one.” However, a few participants are very interested in having sexual intercourse. Natasha, in particular, states her desire “To have sex intercourse sex.”

It is important to emphasize the distinction between sexual experiences for the purpose of enhancing intimacy with another person and sexual experiences for the purpose of physical pleasure and release. Oscar and Paul have both expressed a need to experience the physical aspect of their sexuality. Oscar’s guardian has given him permission to watch pornographic movies. Paul is in the process of being trialed for a self-activated mechanical device to assist him with masturbation. While sexuality for physical release was not a commonly articulated goal in this sample of IWDD, experiencing sexuality can be an important aspect of a person’s quality of life. Prevention from experiencing one’s sexuality for those who wish to, and are deemed legally capable of providing consent, is also a social justice/human rights issue. Sexual activity may be prevented for those who need facilitation in order to do so. This concept will be explored further under the Barriers (to sexual expression section).

**Bisexuality.** Two participants report having experienced bisexual relationships although each of them is currently interested in someone of the opposite sex. Sofia has experienced sexual intimacy with both men and women. She discloses:

I’ve dated women because with a lot of women I had more emotional connection than I did with men because not just for the physical aspect but the emotional

aspect. They're a lot more compassionate than men and more understanding to where a lot of men are not. They don't understand what a woman wants or needs emotionally physically mentally otherwise you know. In a lot of ways I will always be attracted to the same sex physically, but emotionally, I don't know. Maybe I might have a physical attraction or an emotional attraction to that person but I don't know. It was just if I fall in love with a woman I fall in love with a woman.

Sofia is a survivor of several domestic violence experiences with male partners. This circumstance unfortunately is congruent with research indicating that IWDD are at increased risk for victimization and abuse from intimate partners (Nosek et al., 2006). Some trauma persists from those relationships. The above quote indicates Sofia's sense that the compassion and emotional connection she experienced with women had been absent from earlier abusive relationships with men.

**Barriers to sexual expression.** A few participants report barriers related to privacy and/or functional limitations in being able to experience their sexuality. Participants in this study need assistance with all activities of daily living. In order for the participants to engage in sexual activity such as intercourse or to engage in self-masturbation, there would need to be a support person willing to facilitate this activity.

Staff attitudes' have been unsupportive towards this type of assistance due to myths and misperceptions regarding sexuality in the population (Aunos & Feldman, 2002; Christian, Stinson, & Dotson, 2001). Myths and misperceptions run the gamut from the myth that IWDD are childlike and as a result asexual, to the other end of the continuum where they are perceived by others to be sexual predators due to their lack of

impulse control. In both scenarios, the direction educators, parents and caregivers lean towards is that of ignoring IWDD's sexuality. Negative attitudes towards sexuality in IWDD create barriers for them to receive education about sexuality and to learn appropriate skills in order to decrease their vulnerability and to be able to protect themselves from victimization, abuse and STI's (sexually transmitted infections).

Further, negative attitudes towards sexuality in the population by parents and educators become barriers for IWDD to receive sexual education. Sexual education has often been an afterthought or a neglected foci for IWDD (Evans, McGuire, Healy, & Carley, 2009). Educators and parents are reluctant to provide this type of education (Wilkenfeld & Ballan, 2011). In addition, parents are in denial and fearful of planting ideas in their children's minds which might increase their children's susceptibility to victimization by others. As a result, adult IWDD often have limited knowledge about sexuality and birth control methods, and other issues related to their sexuality. Maury cites his reasons for not engaging in sexual relationships due to his fear of making a woman pregnant:

Yeah I mean the person was handicapped to begin with right so once you go on to want to have a sexual relationship...I didn't feel comfortable with that. To this day I don't feel comfortable having sexual relationships with people because what if I make a mistake ...I don't want to be a dad.

Maury's statements indicate that he is uninformed on safe sex practices and birth control methods. Sexual education on these topics would remediate his (and others') fears.

LND patients have additional dilemmas to resolve in experiencing their sexuality. They are prone to self-injurious behaviors and are of risk to others due to their lack of

impulse control as a function of their genetic condition. As a result, they are in safeguarding equipment for self-protective purposes and for the safety of others. Paul laments how being strapped to his chair creates a barrier for engaging in sexual relations with his girlfriend: “No [we don’t have sex]. They’re afraid I may hurt [her]...my social worker and her social worker and my PCA. So the most we can do is hold hands that’s it.” Oscar who also has LND responds to the same question on why he is not having sexual relations: “My behaviors.” Roger, a third person with LND, says “I can’t.” Paul relates his frustration at being unable to have sexual intercourse:

Bonnie: I just wanted to make sure I understood you correctly okay so that’s something you would like in your life you’d like the physical act of sex, intercourse?

Paul: Intercourse.

Bonnie: And that’s prevented by your disability because of your behaviors?

Paul: Yeah.

Bonnie: Yeah is there any way that you can be intimate with somebody?

Paul: No and it’s frustrating...Frustrated that I can’t have sex.

In summary, various barriers prevent participants from having a sexual relationship with others. These range from attitudes of caregivers and parents barring IWDD from education, to the need for a facilitator to assist them in getting in positions (Mona, 2002). Perhaps, due to the fact that these barriers are so vast and overwhelming, participants receive an implicit message that they should not be experiencing their sexuality. Experiencing their physical sexuality was found to be of concern for only a small proportion of the participants involved in this study. Participants were far more interested in becoming involved in romantic relationships in comparison to sexual



relationships. Most, if not all, participants were in, or expressed an interest in becoming involved in, a romantic liaison.

Here is a reflection by Tanya, a particularly articulate young woman, who poignantly speaks of her desire to have it all, intimacy with both the emotional and physical elements:

Most people in the real world don't think we have special desires 'cause some of us can't speak and say we want to have sex and want to be with that special someone to love me and have that whole package but don't take it for granted. We do think about sex and having [that] special someone for the rest of your life and [having] intercourse. We have the same needs the same five senses. We are humans.

### **Romantic Relationships**

OPEN CODE	Example Statement
Hopes for the future	For the future yeah but not right now...I want to look for that special someone.
Frustration/ Disappointments	I feel uncomfortable just knowing that I'm still without a girl.  But I know I could have it even in a wheelchair but I often think the emotional (?) who would want me.

**Hopes for the future.** Most participants report an interest in having intimate/romantic relationships and finding a significant other. Several report that they are currently in such relationships. Participants define romantic relationships as consisting of: holding hands and spending time together at the Adult Day Programs. Some only sought the sexual relationship within the context of a romantic relationship. Frank reflects on his hopes for having a special relationship but fears his wheelchair

status may be off-putting to potential romantic prospects: "Perhaps, but it has to be the right [person]...they might overlook me (indecipherable). I'm in a wheelchair."

Grace hopes that she will be able to have more intimacy with her boyfriend in the future: "Not here yet but in the future I hope to." Oscar also longs for a girlfriend, he states in response to a question on what he would wish for in the future: "My own girlfriend that doesn't want me just for my money." The caveat here is that there is a good bit a soap operatic drama within the MEC community. There are frequent occurrences of cheating on each other, and using others for gain. In this case, Oscar feels a young lady used him to buy her jewelry and then unceremoniously dumped him. Hence, disappointments in romantic relationships are pervasive here, as in any close knit, compartmentalized community.

**Frustrations/disappointments.** As important as relationships are for participants, when they do not go as planned, they become sources of frustration and disappointment. Relationship disappointments as a code surfaced forty-two times over the transcriptions. Jaleel observes that when girls see him in the wheelchair, the wheelchair is a turn off for them despite his having other desirable personality traits, he states:

Yeah, I'm a smart guy. I'm a well-educated guy. It has nothing to do with being stupid, being not able to do anything. It has all the stuff to do with seeing the wheelchair. When they see I need help with something that turns them off.

Frank reflects on his perception of a disparity in cognition between himself and several romantic interests:

None of them have really panned out because a couple of relationships that I've had one when I lived here [MEC] one when I lived at home. It's a few times I have felt like their cognitive abilities are not up to the same level [as mine].

Frank implies that he continues to actively search for partners with whom he can be in satisfying relationships although he is constrained by his limited exposures to potential partners who do not have cognitively disabilities. Here, again, having limited social contexts impacts achievement of goals in the realm of intimacy and romance. The preceding comments illustrate that when IWDD attempt to become involved in romantic relationships they oftentimes result in frustration and disappointment when these relationships do not pan out. Participants who struggle with medical, physical and environmental barriers have difficulty cultivating these intimate bonds with romantic partners who are willing to accept them despite their disabilities.

Further removed from self, a different set of processes emerge in connection to unknown others which relates to community engagement. Stigma and alienation associated with visible disability impact unknown others' perceptions; IWDD believe they are perceived as an 'other' in the broader community. This perception affects the ability of IWDD to become socially accepted and integrated into the community at large.

Participants develop behavioral strategies to cope with perceived ostracism which include maintaining valued relationships with 'known others' (such as: family, peers and caregivers) to help traverse the divide into wider social contexts. In addition, IWDD seek to establish relationships with 'unknown others' through work, volunteer activities, participating in religious venues and performing in various community contexts. Gaining familiarity with unknown others paves the way for breaking down their prior

misperceptions and enhances IWDD's feelings of inclusion. Being included in social environments after taking active steps to involve themselves in those environments serves to expand identity complexity and enhance IWDD's self-concept.

### **Reconciliation in Reaction to Unknown Others**

The task at the extra-personal level is *Achievement of Acceptance/Community Integration vs. Isolation/ Loneliness*. This theme encompasses the various ways participants actively work to integrate into social contexts, or not. At the MEC, a facilitated arts program provides a venue for IWDD to engage unknown others through showcasing their artistic creations in a positive, self-affirming manner.

#### **Community Integration**

OPEN CODE	Example Statement
Participating in the community i.e. Having a job, volunteering, going to college	Work I always look forward to going to work.
-Public performances -Art gallery showings	I've been invited to places to see my art work. I've performed in different venues.

**Participating in the community.** Lipak (2008) reviewed research on the health and well-being of people with cerebral palsy (CP) in Denmark. He concluded that people with CP have less participation in society which is associated with a diminished sense of well-being. Well-being here is defined by factors associated with participation in society: being educated, being employed, living independently, having romantic and sexual relationships, participating in leisure activities as well as in achieving individually defined goals. People with disability are less likely to engage in those activities associated with well-being. Lipak advocates a person-centered approach in promoting

community engagement for those with disability in order for them to achieve this sense of well-being. In concert with these propositions, participants in this study strive towards achieving community integration as a goal for successful adaptation and life quality.

Most participants report a goal of obtaining employment in the community as the following quotes indicate: “I would like to have a job,” “Hoping to get a job,” “I want to be a fashion designer,” “[I would like to] go back to work. I mean not only did I get paid for it but I got to travel more.” Being employed is a productive activity where one gets paid for performing a task. In addition, to earning wages, employment provides a community context for developing work related relationships and perhaps friendships with others.

Maury often struggles with his self-perception as someone with disabilities. He derives much pleasure out of his community activities. He volunteers in a senior citizen home and here he articulates his sense of satisfaction in this role: “I’m helpful to others. If somebody needs something, if they come to me, I’ll make sure that I help them get what they need.” He is also a member of a Jewish congregation in the community where he is accepted by the others in the congregation and “fits right in.”

Joe enjoyed his previous job at a book store, as well as his affiliation with the Knights of Columbus, a Catholic fraternal organization. While currently unable to participate in either of these community venues due to medical setbacks, he refers to both as positive and important roles he held in his life in the past and ones that he maintains hopes of reigniting in the future. Community participation is clearly an important activity for IWDD. When participants are involved in community events in accepted and valued

ways, such as through displaying their art in galleries or performing in public venues, they experience enhanced self-concepts and identity complexity.

*Public performances (gallery showings, performances).* Participants gain satisfaction from being productive, being appreciated by others, and maintaining a higher perceived social category than others who are non-artists. Participants who are involved in the facilitated arts program are offered the opportunity to showcase their creations in public domains such as public libraries, art galleries, internet sites and at performing arts centers. Showcasing art in gallery settings provides people in the public arena the opportunity to interact with participants, not as disabled others, but as talented artists. Interacting with others in the community in social roles such as coworkers, fellow congregation members, volunteers, club members and other positively perceived roles, affords IWDD opportunities for positive interactions with unknown others. Research supports the notion that quality contact, rather than the amount of contact, with marginalized social groups diminishes prejudice towards those groups (McManus, Feyes, & Saucier, 2011). Quality of contact here implies positive social interactions between groups such as those types of contacts referenced above.

Maury values his participation in various art gallery showings as a featured artist. He acknowledges that when his paintings are on display, art gallery visitors don't see him as a person in a wheelchair; he is seen as an artist. Shannah, Sofia and Tanya are talented wheelchair ballet performers. They value those occasions they are out in the public eye enjoying unknown others' admiration and applause. Gallery exhibitions and performances of IWDD in public domains afford them the opportunity to engage with unknown others in a positive manner. In addition, it provides the opportunity for

unknown others to develop ‘cognitive adaptation to the experience of social and cultural diversity,’ as described by Crisp and Turner (2011). Crisp & Turner (2011) posit that the experience of social and cultural diversity (i.e. exposure to diversity) combats stereotyping processes. Specifically, increased exposure to others who are different from the ‘norm’ or the general population paves the way towards achieving greater levels of tolerance, acceptance and general adaptation to their differences. Participants in this study seem to recognize this process and seek ways to become involved, known and subsequently accepted in various social contexts. Alternatively when community acceptance and integration is not achieved, participants are isolated and alienated and subsequently withdraw from their greater social communities.

### **Community Isolation**

OPEN CODE	Example Statement
Social barriers (stigma/misperceptions)	People are afraid because they think we’re diseased or contagious.
-Being mistreated	I’ve been put down.
-Being misunderstood	People don’t understand.
Environmental Barriers	I would like to go into the little cafes but they’re so old they’re not accessible.

**Social barriers.** Various social barriers prevent successful integration for IWDD into wider community contexts. When acceptance and integration are not achieved, participants report being mistreated and /or misunderstood by others. Social exclusion has been theorized to be a result of an evolutionarily derived process to avoid disease. Participants are cognizant of this reaction as Tanya states: “People are afraid because they think we’re diseased or contagious.”

As briefly referenced in Response, Park, Faulkner, & Schaller (2003) review literature which outlines people's behavioral responses to those with physical disabilities. These responses include: avoidance, disgust, anxiety and physical discomfort. There may be an evolutionary aspect attached to this reaction in preventing a person from contracting disease or with regards to decreasing the likelihood of passing on genetically inferior traits to future generations. Park, et. al. (2003) posit that information received from the social context impacts a person's perceptions of their vulnerability to contract disease. They suggest that when characteristics of a social context are perceived to decrease the likelihood of contagion, then the avoidance behavior or prejudice response to those perceived as being afflicted is decreased.

Quality of contact, as posited by McManus, Feyes and Saucier (2011), may be one of those characteristics of a social context which impacts unknown others' perceptions. Quality of contact can be defined as those positive interactions which occur in gallery showings, work, religious venues, etc. which decrease others' perceptions of their vulnerability to contracting disease and results in a decrease of those negative avoidance responses towards IWDD. However, when contact occurs in environments which do not cultivate that level of quality of interactions, unknown others feel threatened. Their behavioral responses result in social exclusion of IWDD and subsequently in IWDD being mistreated and misunderstood.

***Behavioral responses to being mistreated.*** Participants report being ostracized, stereotyped, misunderstood and misrepresented during interactions in the larger social community. Carl states "I've gone out with friends of mine or people from the group home and we go out to eat and they don't like people [like us] coming in and they ask to



be moved.” Carl reacts behaviorally to his perception of ostracism and rejection by others in the community. He fights back at this perceived ostracism by verbally challenging those others who are asking to be moved. He states “...come on, what do you want us to do here.” He clearly is requesting those unknown others to offer him an explanation for their aversion to being seated in close proximity to him in a restaurant. Sofia reports being maligned and verbally abused by others: “I’ve been called names ‘hunch backed’ because of my scoliosis; I’ve been put down.” This type of reaction by others results in Sofia becoming defiant and lashing out at those in the community she perceives as maligning her.

***Being misunderstood.*** Participants are often misunderstood by others in the community due to spasticity secondary to their cerebral palsy diagnosis. This results in expressive language difficulties which literally make them hard to understand by those not familiar with their speech patterns. Tanya relates what it was like for her to get services over the phone: “Another thing that is difficult is calling for services for help. Some people don’t have patience and they hang up the phone on me. People are rude and nasty. That is the cruelty of the reality of life.” As a result, Tanya has withdrawn from seeking help in this manner.

Blair experienced trauma during a medical crisis. She was hospitalized and due to her severe expressive language impairments, she was unable to communicate her severe pain and discomfort to medical staff. MEC staff who visited her in the hospital were able to intervene on her behalf, but she carries the emotional scars of those experiences with her. While understanding that the hospital staff were trying to help, she felt discounted, overlooked and dehumanized. She states “They don’t listen, they don’t hear.” As a

result she experienced unnecessary suffering. In Blair's case, this experience empowered her to educate others about her condition and rally a support network to assist her in communicating with unknown others. Blair has made contingency plans to facilitate her ability to communicate her needs to unknown others if/when she needs to be hospitalized in the future.

Misperceptions, stereotyping processes and perceived sense of alienation impact participants' motivation for becoming actively involved in the outside community and result in either withdrawal and isolation from participating in extra-personal interactions (as reconciled by Tanya) or in developing strategies to combat misperceptions and misunderstanding (as reconciled by Blair). As discussed in Recognition, 'how others see me' is an important emic code referenced by participants in describing aspects of social interactions that impact their self-concept and subsequent behavioral responses. In addition to the various social barriers to community interactions, physical/environmental barriers continue to exist which prevent access to various community settings.

**Behavioral responses to physical/environmental barriers.** Doris lives in a group home in a quaint, historic town. She reflects on her desire to enjoy her town center: "They say Running Brook is a very nice town and I would like to go into the little cafes and things but they're so old they're not accessible." Henry echoes his frustration at having limited ability to access various settings: "Other than going into old buildings, you know and seeing like...that [they] aren't accommodating... that aren't covered by ADA because they were built before the Americans' with Disability Act."

The next few quotes indicate similar types of environmental barriers which prevent IWDD from interacting in their community environments. These barriers

continue to exist despite the enactment of the ADA policies towards creating accessible buildings. Maury states “Well there are some days like if I wanted to go to a building sometimes I wish I could pull the handle and open the door by myself but it’s hard.” Sofia reports her frustration at the limited number of handicapped accessible parking spaces among other problems she encountered on a recent mall excursion: “Trying to find parking spaces, trying to find tables, going shopping.” Shannah types out experiences in accessing her community “I CANNOT GO EVERYWHERE.”

Participants are limited in their choices of commercial establishments that they may utilize in their communities due to lack of accommodations and access. Such barriers impact quality of life, exposure to varied social contexts and ultimately impact complexity of self-concept and life quality. While some participants may withdraw and isolate in frustration at the lack of accommodations available, others continue to research accessible environments, explore ways of navigating inaccessible buildings and advocate for modifications to be made.

In addition to environmental barriers related to access, direct observations of this population indicate that there are barriers related to IWDD’s body schedules and dependency on others for ADLs (activities of daily living). The next couple of quotes indicate their difficulties in participating in a community program. Doris explains “that’s a very hard thing for me to be on time cuz uh you can’t schedule your body functions to be on time.” Joe reports being limited due to his need to wait on others, he states “I would like to go out a lot but my being disabled stops me from that because I always have to wait for somebody to take me out instead of me trying to do it myself.” Doris and Joe have resigned themselves to not participating in various community activities due

to their physical limitations. The struggle to persevere wasn't worth the effort and frustration encountered in being dependent on others. Reaching a degree of resigned acceptance of their situation decreases their ability to enact valued roles in various social contexts. This further prevents them from achieving Acceptance in community social circles and they become isolated. Hence, various barriers exist which preclude IWDD's ability to participate fully in their communities. These include social barriers of stigma and misperceptions, environmental barriers preventing access to various settings and finally barriers related to their own medical/physical limitations.

As discussed in Response, being included in social groups provides protection in the form of resiliency against trauma and loss. When people perceive that others are accepting and maintain positive perceptions towards them, this affects how they feel about themselves and their sense of well-being and life quality (Baumeister et al., 2005; Crisp & Turner, 2011; Richman & Leary, 2009). Further, when they are accepted, they will actively try to get out into their communities and/or work to build more opportunities to engage with others. Negative reactions from 'unknown others' include: stigmatization, avoidance and rejection (Park et al., 2003; Richman & Leary, 2009). These reactions may impact the rejected person's ability to regulate behavior, mood, and ultimately goad them to isolate themselves or withdraw from exposure in the greater community which then may diminish their self-concept by limiting their exposures to various environmental contexts.

Participants adopt various strategies which help them cope with negative perceptions of others. These include developing, maintaining and strengthening relationships with both known and unknown others, enacting valued identities, and

gaining an overall sense of control and self-determination. Some IWDD persevere to forage out into community environments which were previously (or currently are) difficult to navigate. Participation in various social contexts affords IWDD the opportunity to develop relationships and gain familiarity with unknown others. Through these exposures, participants develop relationships which enhance their sense of belonging and ultimately identity complexity and self-concept. Barriers (as previously outlined) inhibit some IWDD from fully gaining exposure and integration to various social contexts yielding implications for diminishing identity complexity and self-concept. Failure to achieve social acceptance and community integration negatively impacts their sense of well-being and life quality.

## **Chapter 7. HICLAS Analytic Thematic Categories**

### **HICLAS Analysis Overview**

As discussed in the Methods section, hierarchical classes (HICLAS) analytical strategy consists of a series of short, structured surveys. These surveys guide participants in identifying and describing the various roles, hobbies, activities and relationships that are important to them (both positive and negative) (Stirratt et al., 2008). I will provide a brief review of the process here, but for further explanation please see the more detailed description in the Methods Section (Chapter 3).

First, the participants are asked to create an inventory of various identities associated with social roles inherent in relationships with others and in various social situations. Roles are comprised of relational, avocational and spiritual domains. Next, they are asked to rate each identity on a scale from 1 – 5 indicating importance of that identity to the person's self-concept in order to streamline them down to 12-16 as scored highest by the individuals. At this stage in the process, the participants are asked to characterize each of their identities with a set of features describing themselves when enacting that identity (e.g. such as 'happy, sad, tired'), thus creating an individualized vocabulary of approximately fifty items. In the final phase they are asked to rate each set of identities in association with the various features as to whether that feature is present or not for the particular identity.

Data are organized into an identities X features matrix consisting of 12-16 selves by approximately fifty features and subsequently analyzed using the computer-based 'HICLAS' algorithm. The algorithm clusters the various identities/roles/avocations based on co-occurrences into a hierarchical organization in relation to various features as

described by participants when enacting those roles. I used a Rank 3 solution which distributes the identity clusters and the feature clusters into three hierarchical levels. Identities which rise to the cluster located in the top hierarchical level are of the most self-perceived importance to the person in that they encapsulate the other identities lower down in the structural hierarchy as well as the overall span of associated features (Gara & Rosenberg, 1979). In effect, a structural map is produced which illustrates the participant's self-ascribed importance of each identity and their associated features. Identities which surface at the prominent (highest) level encompass most of the other identities and associated features and have been posited to serve an organizing function for the individual.

While this procedure has been used with individuals with severe physical disabilities (Robey, 1997) and with mental health issues such as depression and schizophrenia (Robey et al., 1989), its effectiveness in populations of those with mild cognitive impairments was uncertain. Participants in this study have cognitive levels that range from mild cognitive deficits to borderline normal intelligence as indicated by their I.Q. scores. It was unclear if there was any value in using HICLAS or even whether participants would be able to complete the surveys.

Participants, in fact, were all able to complete the sequence of surveys despite some challenges in understanding the ratings and creating a sufficient vocabulary list to describe themselves in enacting their various roles. As previously mentioned, I used a Rank 3 solution which distributes the identity clusters and the feature clusters into three hierarchical levels. At the "rank 3" solution, most structures evidenced all three levels of hierarchical arrangement. In contrast to other structures depicted in the literature, some

of the clusters within some of the levels were absent (“empty clusters”) for several of the participants creating a more sparse overall structure than what is typically seen with other populations.

The goodness of fit (GOF) statistic generated by the HICLAS algorithm indicated that in all structures the attributions of features to identities are accounted for in the structural representation (De Boeck, & Rosenberg, 1988). The GOF statistic in this sample ranged from .694-.920 with most in the .800 range. A .800 indicates that 80% of the participant’s features to identities are accounted for in the HICLAS structural map and generally is accepted as meaning that the structure is a good fit for the data.

### **Verification of Qualitative Data**

HICLAS analysis is utilized in this study as a mechanism to triangulate data obtained from the qualitative interviews. Qualitative studies obtain strength and rigor from triangulating findings with additional sources of data. Many of the themes which emerged from the qualitative interviews are reflected in the HICLAS analytic structural models.

An overarching research question for this study is how individuals with disability make meaning of their identities? For these participants, identities (roles, avocations, affiliations) that are of self-ascribed importance become positioned at the top of their structural map. Multiple identities are associated with increased complexity of self-concept which has been implicated as having protective aspects for an individual (Linville, 1985). This study seeks to explore the role of identity complexity in enhancing life quality and sense of well-being. HICLAS analytic structural maps provide a visual depiction of the multiple roles that participants identify themselves enacting in



association with their feelings about themselves when enacting those roles. Hence, this method seems ideally suited for triangulating the qualitative information.

I shared participants' structural maps with all after they completed the entire interview process, both HICLAS surveys and qualitative interviews so as not to impact the data collection. Participants were very interested in seeing their identities mapped out in the structural depiction that is created through the HICLAS algorithm. Some participants asked to have a copy to show their friends, families and social workers. Participants indicated that the structures reflected themselves accurately for the most part. Frank is a devoutly religious born again Christian. He has a sparse structure which focuses in on his religiosity. His identity as a born again Christian was in the prominent level of his structural depiction. His feature of 'giving testimony to other people' was an attribute which is associated with all of his other features and identities. Frank seemed to feel this was a true representation of his sense of self. Hence, participants were easily recruited to member check the data derived from the HICLAS process. For IWDD (individuals with developmental disabilities) who have cognitive deficits which may impede their ability to review lengthy transcriptions or analysis within the actual dissertation, the structural map that evolves from the HICLAS process provides an easy and interesting representation of data for participants to review and comment upon.

**Primary themes identified in HICLAS (in ranked order).** The following is a list of the various identities which were most frequently referenced in the HICLAS surveys.

1. Relationships (emerged in 20 structures) at the top hierarchical level in 11 structures

- a. romantic relationships (emerged in 9 structures) at the top in 2 structures
- 2. Disability identity (emerged in 20 structures) at the top in 8 structures
- 3. Sexual identity (emerged in 18 structures) at the top in 5 structures
- 4. Artist identity (emerged in 16 structures) at the top in 3 structures
- 5. Being a mentor/role model/teacher/helping others (emerged in 9 structures)
- 6. Being productive (emerged in 6 structures)
- 7. Medical issues (emerged in 4 structures)
- 8. Being normal (emerged in 3 structures)

***Relationships.*** In this sample, one of the two most frequently observed identities to emerge is: participants' sense of themselves in connection to others with whom they have relationships; this sense of self emerges in each and every participant's structural model. Some examples include: "myself as a friend," "myself as a sister." This observation supports the information obtained in the qualitative interviews where 'being with my family and friends' was the most frequently coded theme throughout the interviews.

In eleven out of twenty structures, this identity surfaces at the top of the structure encapsulating all of the other identities and features associated with those identities. Identities that emerge at this level are considered prominent to the individuals' self-concept. This finding corroborates information obtained from the analysis of participants' qualitative interviews. Relationships with family and friends were prominent aspects of participants' lives and when they expressed the ability to nourish these relationships, typically this was associated with positive feelings of connectedness and inclusion and an overall sense of belongingness and well-being.

To further illustrate this connection, Jaleel's prominent identity cluster emanating at the highest level in his structure holds four identities related to himself with others: 'a brother to my sister,' 'with Blair,' 'with cousin Sharif,' 'with my teacher.' This identity cluster is prominent in that it rises to the top hierarchical level in his structure and encapsulates two out of three lower identity clusters and five out of six feature clusters including both positive features (e.g. 'brotherly,' 'awesome,' 'proud') and negative features (e.g. 'not wanted,' 'treated differently'). Jaleel spent much of his qualitative interview speaking simultaneously of how important his family of origin is to him along with his disappointment at their not being there for him. He describes himself as a socially oriented person and relationships with others comprise a large portion of his discussion of things that are important to him in his life. This appears to be well represented in his HICLAS structural depiction.

***Disability identity.*** In addition to relationships, the 'disability identity' was another prominently articulated identity that emerged in the HICLAS surveys. This identity rose to the top of eight participants' structures and was expressed by every participant in this study. The 'disability identity' is associated with a broad array of features both positive and negative. For example having a disability identity was associated with seemingly contradictory features such as: 'focus,' 'freedom,' and 'pushes me' as well as, 'heartbreak,' 'not accomplishing,' and 'bitterness.'

Three participants did not independently articulate their sense of having a disability identity. In order to establish continuity with the other participants as well as to explore one of the primary research questions: *'how does the disability identity manifest itself within IWDD's identity structures and how does this impact their overall sense*

*well-being and of life quality?*’ I inserted this ‘disability identity’ into their list of identities for them to rate and ascribe features to. Interestingly enough, despite the artificial insertion of this identity, it still became integrated within their structural maps as opposed to becoming residual. Residual identities are those expressed by participants which do not properly fit into the structural model based on participants’ attributions of features to a particular identity. Specifically, despite the fact that those participants did not independently articulate the disability identity, when inserted within their surveys, they attributed many features connected to that identity and it rose to a prominent level within their structures.

***Sexual identity.*** Sexuality was expressed by eighteen participants. ‘Myself as a heterosexual male’, ‘myself as a bisexual female’ and ‘as a straight male’ are examples of the way participants expressed their sense of sexual identity. This identity was associated with mostly positive features. However despite almost all participants expressing their sexual identity, it only rose to the top hierarchical cluster in five participants’ structures. Sexuality did not appear to be a strong focus for participants in this study. They appeared to be more interested in achieving emotional/romantic connections with another person which also is consistent with findings in the qualitative surveys.

Participants did not generally express an overriding need to experience their physical sexuality but did report a strong interest in developing and maintaining romantic relationships which is consistent with the qualitative interviews. So apparently, while identifying themselves with a specific sexual orientation was prevalent for participants, the need to physically express or experience that orientation was not evidenced in this sample. However, it is possible that the HICLAS process doesn’t capture the nuance of

their sexual identifications since most IWDD in this study are not able to behaviorally enact their sexuality. In addition, as mentioned in Reconciliation, as participants have not been provided with adequate sexuality education and facilitation opportunities, they may have received implicit messages that this aspect of their lives is not something they need to reconcile which may account for the absence of this need for physical expression in their HICLAS structures as well as in the qualitative interviews.

***Artist identity.*** ‘Myself as an artist’ emerged in sixteen participants’ structures and was at the top of the hierarchical map in three participants’ structures. ‘Myself as a writer,’ ‘Myself as a painter,’ and ‘Myself as a wheelchair dancer’ were expressed by participants who describe themselves creating visual art and participating in the performing arts. Participants describe themselves enacting the ‘artist identity’ with positively valenced features such as ‘accomplished,’ ‘expressive,’ ‘being true to myself,’ ‘phenomenal,’ ‘awesome,’ ‘breaking barriers’ and ‘special gift’ as some examples.

Henry has the artist identity at the top level of his structural map. He associates this identity with three out of five other identities and with five out of six feature clusters, again encompassing most of his other identities and features which he uses to describe himself when enacting those identities. Henry references his artistic identity in response to a question: the best way I have to express myself is? Henry replies “art.” Henry has created his own technique which he calls the “splatter effect”. He continues here to describe the process in a philosophical manner: “A lot of my paintings have the splatter effect but that’s because I like splatter painting because splatter painting is like life you know the paint goes where it wants to go as life.” In both the qualitative and HICLAS

interviews, the artist identity emerges as a crucial element impacting Henry's self-concept.

***Identities of lesser prominence.*** Other emergent identities were expressed at a decreased frequency to Relationships, Disability, Sexuality and as an Artist. Just under half of the participants (nine) mentioned being a 'mentor/role model/advocate.' The other identities which surfaced less frequently include: 'being productive (six),' 'having medical issues' (four) and 'being normal (three).' However, despite the lower frequency with which these identities are manifested in the HICLAS series, all of the articulated identities are reflected in the qualitative interviews and appear crucial to IWDD in this study in the development of their self-concept.

The crafting of the qualitative interview was guided, in part, by the format of the HICLAS survey sequence which asks for participants to identify important aspects of their lives and then describe themselves when enacting those roles. Hence, the various themes voiced in the HICLAS surveys are anticipated to be echoed in the qualitative interviews which might account in part for this continuity of themes. I attempted to counteract effects of instrumentation; half of the participants were administered the HICLAS series first, followed by the qualitative interview. This sequence was reversed for the other half of the sample.

Regardless of the sequence of administration, these identity categories are all evidenced in both the HICLAS series and the qualitative interviews. It appears as if the HICLAS themes mirror the qualitative data in content. The qualitative surveys indicate that relationships are the most important aspects of their lives, as well as an overriding desire for acceptance and integration for IWDD in this sample. These themes may be

encapsulated by the HICLAS themes of “myself as a ...brother, sister, son, or daughter” and “how others see me, being normal” respectively.

‘Acceptance of the disability’ was cited in the qualitative interviews ‘by myself’ (forty-four times from eleven different participants) and ‘by others’ (forty-four times from eleven participants). As Tanya articulates in her closing comments at the end of the qualitative interview “[I would like] just for people to think we’re just like them to think outside of the uh box to be open minded to get to know someone in a wheelchair.” Tanya has in her HICLAS structure an identity of herself ‘as a person in the community’. She has many opportunities to be in the community as she resides with her family of origin and is a talented artist who frequently has gallery showings and performances in community venues. This identity is associated with features describing what being in the community as an artist is like for her: ‘big thrill,’ ‘everything to me,’ ‘pissed off,’ ‘frustrated,’ and ‘letting myself out there.’ Clearly she associates both positive and negative attributes to this identity of herself as someone out in the community. Tanya’s qualitative interview explored her experiences in various community venues where she displays her art work. She has had both positive and negative interactions with ‘unknown others’ in these environments. As previously discussed in the preceding chapters, she has been treated with acceptance and aversion and has described her sense of others’ reactions to her as ‘like an alien’, ‘like I’m contagious,’ and ‘they look at me weird.’ It appears the HICLAS survey captures this dichotomy of acceptance/aversion by unknown others.

The enactment of valued social roles such as being a mentor/role model/advocate mirrors the tasks of achieving cognitive self-appraisals within the process of Recognition.

Encapsulated by the axial code of Hierarchy; (thinking about themselves in higher social categories) within Recognition and also within the process of Reconciliation (the enactment of these higher perceived social categories), participants sought to elevate themselves into a higher perceived social categories by adopting valued identities. As mentioned in Recognition, various protective aspects are associated with ascribing to higher status social categories as an adaptive strategy towards achieving a sense of social inclusion. For example, the identity of being a mentor/role model was cited in nine structures. ‘Being a mentor’ as a code surfaced twenty-seven times in the qualitative surveys.

Blair has an identity in her structure which is labeled “being an inspiration to others.” She associates this identity of being an inspiration to others with characteristics from four out of seven feature clusters. Some of these include: ‘educational,’ ‘in a free-minded world,’ ‘fearless,’ ‘being true to myself,’ ‘fierce,’ and ‘proud.’ All of the feature clusters in Blair’s structure which are associated with this identity are positively valenced indicating that this is a positive identity within her self-concept.

Allan also has “being a mentor/role model” in the second level within his identity structure. This particular cluster is also associated with two lower identity clusters and five out of seven feature clusters (all either positive or neutral in valence). Some features he directly associates with the identity of role model/mentor include: ‘pushes me,’ ‘occupied,’ valued,’ ‘inspirational,’ and ‘so much more to me.’

Ivan is a motivational speaker. He has been engaged by various agencies to speak in front of groups about having cerebral palsy and how he copes with his condition and has successfully started up his greeting card company. He attributes ‘helping others,’



educating,' 'helps me,' 'productive,' as some of the features associated with the identity of 'being a motivational speaker.' Blair, Allen and Ivan maintain the role of mentor/role model and express this role in their qualitative surveys. In all three cases, the role of being a role model/mentor is associated with positive features and the majority of feature clusters within their structural maps.

Participants indicate their desire to be productive and that barriers, such as medical issues, impede them from achieving their goals. The sense that I received from both sets of interviews is that barriers related to medical setbacks present bigger obstacles to achieving goals than those barriers related to their developmental, physical disabilities. This concept of barriers related to their medical condition is referenced in the HICLAS information as 'medical setbacks' as opposed to 'barriers' in and of itself, as a category, which is not expressed in the HICLAS data. Grace has a negative identity of 'one who is catheterized.' This is an unpleasant but crucial element of her day to day existence. She associates this identity with features which include 'depressed,' 'gets old,' 'hard,' 'working things out,' and 'strong' encapsulating both negatively valenced but also positive attributes.

Allan, who has spina bifida, is a participant who I refer to in previous chapters as spending months at a time on bed rest. He discusses at length the impact that this medical barrier has had on his life in the way he thinks, feels and then is prevented from reconciling various roles in his life. His HICLAS structure reinforces this theme of medical barriers as a pivotal component of his self-concept. At the top of his structural hierarchy, both of his prominent identities encapsulate his focus on his medical condition. He expresses identities of 'being stuck in this life' and of 'having a disability.' In the

second level down, he has an identity of ‘recurrent thoughts about myself not getting any better.’ In the third (lowest hierarchical level), he has an identity of ‘one who has wounds.’ This information is all consistent with his qualitative interviews where he speaks about his medical condition preventing him from moving forward with his goals of having a relationship, moving into a supervised apartment, or getting a job.

### **Reflections on Using the HICLAS Analytical Process**

**HICLAS analysis process:** The initial intent of using HICLAS analysis in addition to qualitative surveys was to obtain a visual depiction of participants’ salient identities and their self-ascribed levels of importance to the individual. In addition, due to the subjective nature of qualitative inquiry, the ability to triangulate the data with another analysis modality is a precursor to verifying the data. Despite this initial rationale, some unforeseen benefits and problems emerge associated with the HICLAS analysis process.

#### ***HICLAS analysis pros.***

1. The HICLAS analysis process turns out to be user friendly with this population for those with expressive language difficulties due to their physical impairments. Responses are not tied to long passages of text but rather short sound bites allowing participants to use language and speech patterns with which they are more accustomed. Some of the participants seem more comfortable responding to the HICLAS survey questions and express themselves in very poetic and nuanced fashions. Blair is an articulate, self-styled author with severe spasticity which greatly impacts her expressive language ability. She describes features associated with her identity ‘as a writer’ as “being in a free-minded world.” She associates some negatively valenced identity clusters with: “Stuck in a box,”

and “Madness.” Doris, a middle aged woman who lives in a group home, expresses a descriptive feature/attribute of “part of the packaging” in association with the majority of her identities in her structural model.

When asked for a word or phrase to describe themselves when enacting a particular role, some participants like Blair and Doris express themselves in a descriptive, nuanced fashion using only few words. However, when responding to open-ended questions characteristic of the interview guide, some participants become stymied and perhaps overwhelmed at the prospect of telling a story. The conversation then turns towards a dialogue with my attempting to interpret their speech or communication device.

2. The HICLAS analysis procedure requires a series of shorter interviews so familiarity and rapport was built over the course of four to seven weeks. As a result of developing relationship, participants express personal information later on in the interview process that they felt uncomfortable expressing earlier on. When interviewing Tanya, I administered the qualitative interview first followed in the next several weeks by the HICLAS series. At the end of the HICLAS sequence, Tanya began to disclose fully fleshed out stories of her experiences, some in contradiction to her responses during the earlier qualitative session. In response to my query as to why the information had changed, she responded “Well I didn’t know you then. I didn’t trust you like I do now.” In addition to enhancing familiarity and comfort, the longer series of interviews also allows me to become more familiarized with participants’ speech patterns and learn how to navigate their communication devices.

3. There is concordance between what emerges over the course of the qualitative interviews and themes that are expressed during the course of HICLAS analysis. It appears that both applications show consistency across data and thus enhance the trustworthiness of the findings in this project.
4. HICLAS analytic process guided me in theory building. HICLAS analysis provides a visual depiction of the hierarchical representations of various identities within one's self-concept and their relation to the various attributes (features) as participants describe what being in the identity is like for them. I have incorporated this association of identities to their features in my theory and have labeled them 'cognitive self-appraisals.' Cognitive self-appraisals are an internally derived conceptualization which evolve from the combination of the multiple identities within one's self-concept and their associated features that they attach to those identities. This construct becomes an important component of the Social Theory Of Identity Complexity (STOIC).

Defining the elements that comprise cognitive self-appraisals allows future researchers the ability to operationalize these constructs and test them using both quantitative and qualitative methods. Specifically, one may define themselves as a mentor and associate that role with positive features such as 'helpful,' 'good,' and 'empowered,' It would be interesting to use self-esteem or self-efficacy surveys to corroborate the association between maintaining positive features in relation to certain identities (such as being a mentor). Having identified components which enhance self-esteem, this information could then be used in therapeutic contexts to reinforce those identities or create opportunities for individuals to develop identities which may hold positive associations for them.

5. Participants are all interested in seeing their structures and having them explained. Many are proud and feel a sense of accomplishment at having created this representational map of who they are. They want to share their ‘structural maps’ with their friends, family and social workers. I was glad to have the opportunity to engage them further in the process and this also provided me with a ‘hook’ to incorporate them into ‘member checking’ to further verify findings as previously stated.

***HICLAS analysis cons.***

1. There were some difficulties in completing the process due to cognitive impairments. Some participants struggle with the part of the process where they have to rate their various identities in relation to their sense of the importance they perceive these identities to hold for them. To review, participants were asked to rate their various identities on a scale of one to five so that we could whittle the list down to the twelve to sixteen most salient identities. Some participants who have lower cognition struggle to understand the concept of assigning levels of importance to their various identities. For example Luis has lower cognition than most of the other participants in this sample. He struggled to understand the concept of rating the identities, so I needed to do a cross comparison of each identity with him i.e. asking him “which identity is more important to you ‘identity A’ or ‘identity B’.”

2. Another struggle relates to expressive language abilities. Participants need to develop their own vocabulary to describe themselves when enacting the various identities. This was a positive for some with higher cognition that have expressive language deficits related to their physical condition (such as Blair and Doris as previously mentioned). Spasticity of muscle coordination and breath control related to cerebral palsy impair some

participant's ability to express themselves in a verbal manner. Alternatively, others have expressive language difficulty related to their cognitive deficits. Participants needed to come up with fifty to sixty descriptors (words/ phrases) for their twelve to sixteen salient identities. This is a difficult task for anyone regardless of cognitive abilities.

3. While the sequential process is of benefit in developing familiarity and rapport for the interviewer and the participant, the lengthy process can become quite tedious.

Participants may lose interest and begin to give rote answers not truly reflective of their situation or feelings about a particular identity. Constant vigilance in watching out for signs of fatigue needs to be maintained by the interviewer. The interviewer needs to check in with participants when responses appear to be inconsistent or irrelevant to the survey information. Participants can be offered a break or end the session and continue on another day. This factor can also be problematic for researchers who have time and financial limits on their data gathering process.

### **Summary**

Using HICLAS analytical method appears to be an effective means for triangulating the information about identities obtained from the qualitative interviews. Themes manifested in the qualitative interviews are echoed in the HICLAS surveys and subsequent structural depictions (see item #4 under HICLAS pros above). I noted in several instances where language seemed to be echoed over different participants. This may be related to participants navigating the same social circles and capturing a cultural manner of self-expression. For example, the phrases: 'ups and downs,' 'seeing the wheelchair,' 'being stuck,' 'part of the package' and 'like family' surfaced across multiple interviews. Requiring people who are not used to using language to express

nuanced information about themselves was a difficult endeavor for some but seemed to bring out the creatively expressive side of some others.

Several benefits associated with the process include first, providing myself and the participant with the opportunity to develop relationship and rapport freeing them to fully express themselves. Next, the process is more user friendly for those with physical impairments which prevent easy articulation of speech. The short responses are easier for those with expressive language impairments who have difficulty with breath control and muscle movements. The HICLAS analytical process provides a concrete finished product (structural map) for the participant to substantiate his/her participation in the study. In addition, the underlying foundational assumptions assisted me in the articulation of the final theory: Social Theory Of Identity Complexity (STOIC) with regard to the identification and incorporation of ‘cognitive self-appraisals’ drawn directly from the HICLAS process. (For further explanation, see item #4 under HICLAS analysis pros above).

These advantages offset the disadvantages related to the sequential interview process which includes the tedium associated with rating twelve to sixteen identities with fifty to sixty descriptors, and taxing cognitive skills in assigning rankings to various identities and creating vocabulary. This is more challenging for those with greater degrees of cognitive deficits.

## Chapter 8. Theory and Conclusions

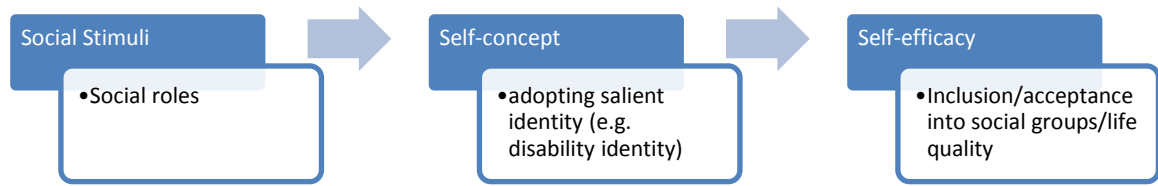
### Synthesis of the Findings

**Overview.** The ability to exert control over one's life and receive accolades and admiration in the wider social community both serve to enhance participants' sense of self-efficacy (achieving their goals) and sense of acceptance by their social communities. Being productive, having the ability to express oneself, exerting control over various aspects of one's environment and nurturing relationships with family and friends seem to be the components most frequently referenced by participants as enhancing their sense of well-being and life quality. As noted in Chapter 2 (Literature review), the literature identifies various constructs as influencing life quality and sense of well-being. Research identifies factors associated with having happy and satisfying lives as including: social relationships (especially relationships with family), choice and independence, involvement in interesting activities, and maintaining valued social roles (such as having a job) (Haigh et al., 2013).

As reflected in Figure 3 below, social roles emerge in response to various social stimuli in the environment. Individuals' self-concepts (negative or positive perceptions of self) are influenced by the varied roles they fill within the communities where they are affiliated. Further, as discussed in Chapter 1, self-concept is comprised of self-esteem (evaluative process), self-efficacy (competency) and the salient identities which may become more prominent depending on particular situations (Bogart, 2014). The process of self-efficacy relates to the ability to achieve goals consistent with one's self-concept.



Figure 3. Pathway of identity development through social inclusion



These processes set the stage for this investigation using several research questions as guide posts to explore the life experiences of individuals with developmental disabilities (IWDD) and what they perceive as enhancing life quality. Having been a practitioner in the field working with IWDD for the past seven years, I was particularly interested in how they make meaning of their lives and what contributes to their sense of well-being. In addition, I was interested in understanding what, if any, impact that participating in a facilitated arts program might yield for these participants.

**Research questions.** Research questions addressed in this study include:

- 1) How do individuals with disability make meaning of their own identity?
- 2) How does the disability identity manifest itself within IWDD's identity structures and how does this impact their overall sense well-being and of life quality
- 3) What are the roles and social contexts that create or enhance identity complexity and how might this affect an IWDD's overall self-concept and sense well-being and life quality?
- 4) What is the impact of creating art on self-concept for IWDD in a facilitated arts program?

The major finding in this study is that IWDD seek acceptance/integration vs isolation/loneliness in their various social communities. This is actually a common goal to all people, even those without disabilities. In the quest of this goal, IWDD have more challenges and less access than individuals without disabilities. IWDD appear to engage in three general processes as they develop complexity of self-concept and seek acceptance in their wider social communities. These processes occur at three degrees of separation (or levels) from self. The intrapersonal level involves the development of cognitive self-appraisals as part of one's self-concept. Two extra-personal levels occur further away from self, processes occur in relation to known others – (such as interpersonal relationships with family and friends); and finally, at the greatest distance from self, processes occur in relation to unknown others (interpersonal relationships with strangers in the community). These processes I label: Recognition (cognitive domain), Response (emotional domain) and Reconciliation (behavioral domain).

Ultimately, one outcome of these processes is the 'Desire for Acceptance/Integration' at micro (i.e. interpersonal interactions with known others – extra-personal) and meso (i.e. community interactions with unknown others– extra-personal) levels which may yield implications at the macro level (societal policy initiatives, theory). Self-concept (the result of cognitive self-appraisals) is impacted by, as well as affects, the resolution of tasks at intrapersonal and extra-personal levels across emotional and behavioral domains. Recognition, Response and Reconciliation comprise components of the grounded theory generated in this study which I dub the Social Theory Of Identity Complexity (STOIC).

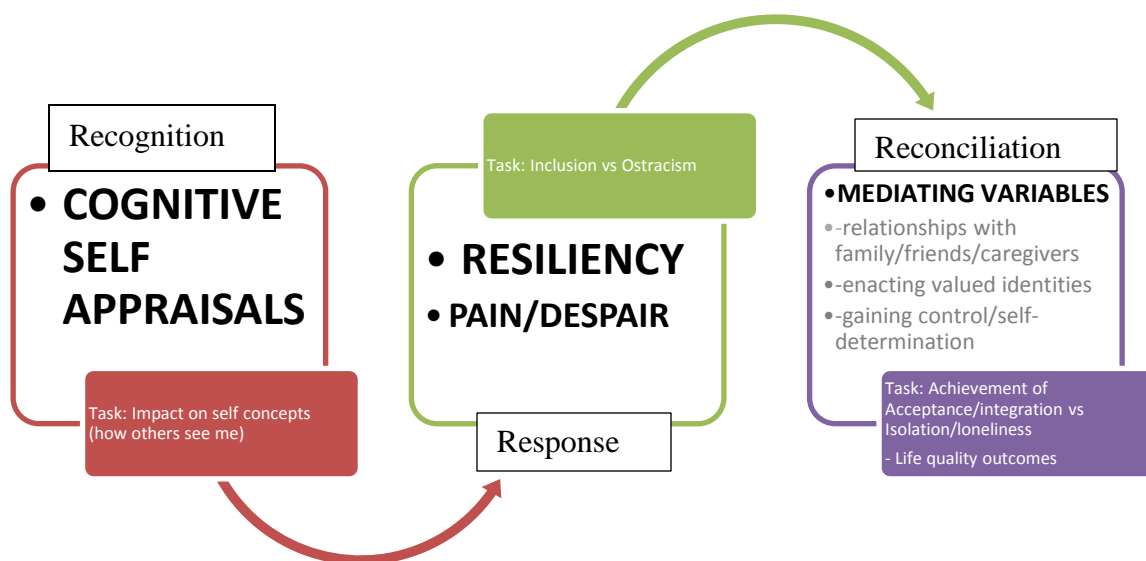
**Social Theory Of Identity Complexity (STOIC).** The three processes of Recognition (cognitive), Response (emotional) and Reconciliation (behavioral) represent threads in a tapestry which are woven together into a cohesive overall theory: the Social Theory Of Identity Complexity (see Figure 4). Recognition is an internal process involving the development of cognitive self-appraisals. These self-appraisals consist of the multiple identities (identity complexity) within one's self-concept along with the features (or attributes) associated with those identities. Individuals are confronted with the task of maintaining/enhancing their self-concept in relation to their projections of how they believe others' see them, as well as how they view themselves through their own eyes. For example, coping with, and adjusting to, disability reflects one type of adaptive Response (Resiliency).

Resiliency is derived from maintaining positively valenced features relative to multiple, diverse and valued identities (identity complexity). Additionally, developing adaptive coping strategies for responding to others' perceptions/ behaviors has implications for an overall sense of well-being. The task that is encountered at the extra-personal levels of Response with respect to known and unknown others is feeling included vs. ostracized i.e. Inclusion vs. Ostracism.

Aspects of coping/adjustment which are related to maintaining interpersonal relationships include: a) the behavioral enactment of valued identities (perceived higher status e.g. 'being an artist', 'being a mentor', and b) gaining control/self-determination and agency in pursuing one's goals. Goals for most participants involve becoming integrated and accepted into social networks. This is a process I label Reconciliation.

These processes of Recognition, Response and Reconciliation are dynamic and reflexive and are the foundational tenets guiding this theoretical perspective.

Figure 3. Social Theory Of Identity Complexity (STOIC)



As stated previously, in the selective coding phase of grounded theory research, the investigator continuously asks questions about the data and refines the theory that has been developed. This is a progressive, reflexive and dynamic process that changes interpretations as additional data are analyzed. The resultant theory emerges from the grounded data. As the analysis progressed, each of the processes identified (Recognition, Response and Reconciliation) became identified as integral to achieving identity complexity and enhancing self-concept for participants in this study. Several underlying assumptions form the foundational tenets of this theory including:

**Underlying assumptions:**

1. One's self-concept is partly comprised of a collection of multiple, context dependent identities. These identities have also been referenced in the literature as: self-representations, aspects, perceptions, appraisals, roles (Cast & Burke,

2002; Deaux, 1993; Stets & Burke, 2000). These identities are hierarchically organized in relation to perceived importance by the person. This hierarchical arrangement typically reflects the particular context that the person is situated in a particular point in time (Roccas, 2003).

2. IWDD are susceptible to being stigmatized and stereotyped by unknown others (Goffman, 1963; Paterson, 2012). My data indicate that their perceptions of others holding negative perceptions subsequently results in IWDD feeling devalued and marginalized. These affective *Responses* impact an individual's affective state of wellbeing and one's ability to interact in (*Reconcile*) various social environments.

3. Identity complexity is associated with maintaining multiple identities which are described by:

- a) Personal characteristics
- b) Social roles

These identities are associated with features (attributes, characteristics, descriptors), that have valence (positively or negatively oriented features such as happy, fulfilled, enriched vs sad, neglected, ignored, respectively) which are also hierarchically organized (Stirrat et al., 2008). This assumption is derived from the HICLAS analytical framework and serves to describe the multiple identities which people hold within their self-concepts.

4. The combination of identities and associated features are referred to, here, as cognitive self-appraisals (development of cognitive self-appraisals: *Recognition*)  
While not an aspect of direct analysis in this study, I propose there is a link

between maintaining positive cognitive self-appraisals, self-esteem, and self-efficacy (two other components of self-concept) (Bogart, 2014).

5. *Response* involves the day-to-day resolutions of the task of Resiliency vs Pain/Despair. Coping with disability and social exclusion is an adaptive *Response* which is associated with resiliency (Thoits, 1995; Uchino, 2004). This has implications for overall sense of well-being (adjustment). When coping is not adaptive, the result is the *Response* of pain/despair. Depression, anxiety, anger and feelings of ostracism and rejection negatively affect one's sense of well-being resulting in pain/ despair. Variables that impact *Response* are tied to how IWDD *Reconcile* those *Responses*. I theorize that they do this by maintaining interpersonal relationships, enacting valued identities (perceived high status e.g. 'being an artist') and gaining control/self-determination and agency in pursuing goals. People without developmental disabilities have greater ability to access and participate in varied social contexts which enhance their identity complexity. IWDD may be prevented from adaptively *Reconciling with* their communities due to an inability to access enriching, fulfilling social environments due to their medical conditions, transportation needs, need for facilitation and assistive technology as well structural access issues in various community environments.
6. *Reconciliation* ideally leads to a sense of belonging and/or self-acceptance (e.g. showcasing art in a public exhibition and enacting an 'artist identity' along with one's other identities –thereby elevating one's identity to a higher social status, 'myself as an artist'). When Reconciliation fails, the result may be withdrawal which leads to isolation and loneliness. Desire for integration into social

environments defines the overriding objective for stigmatized populations in achieving a sense of well-being. Enacting valued roles/ identities and having them accepted by others positively impacts cognitive self-appraisals and self-concept (feedback loop). It is critical to create opportunities for IWDD to develop positive cognitive self-appraisals which they value and can subsequently enact in various community domains. I theorize that these processes will facilitate enhancement of identity complexity leading to positive self-concept and self-acceptance. This creates bridges for positive interactions in the community with unknown others which may then impart feelings of acceptance and inclusion.

***Using STOIC to explain the development of identity complexity.*** Figure 4

represents the processes through which IWDD achieve identity complexity. This figure represents the reciprocal and interconnected nature of the data. The process of *Recognition* is identified first. The task at *Recognition* is developing acceptable (to self) cognitive self-appraisals which are defined as the combination of identities with associated features that cohere to create one's self-concept. Individuals with significant disabilities are reflective and gain understanding over time, a construct I term 'gaining maturity' under cognitive self-appraisals (see Chapter 4. Recognition). They use positive coping strategies to frame their experiences. As outlined in Recognition these strategies include: 'being positive,' creating rationales, using spirituality: for a reason, and embracing their disability identity. In addition, participants gain understanding through time and experiences to learn more about who they are within the context of having disability, as well as in relation to the other identities they maintain within their self-concept, apart from their disabilities.

Participants *Recognize* their various selves (roles, identities, personas) within their self-concept, separate from having disability. Recognition is a process that can only occur through exposures to, and interactions with, one's social environments over time. Maintaining complexity of self-concept, consisting of multiple valued roles in addition to a strong disability identity, appears to be important for resilience and adaptation to environmental assaults such as loss and social exclusion. Desire to be treated "normally" was a theme expressed among participants as they described their relationships with known others. Normality is a relative concept and by being treated as 'normal,' the participants become incorporated into whatever social group they are interacting with at the time.

Participants maintain multiple complex identities related to various social contexts. These identities are described by personal characteristics and social roles which have associated features (attributes, characteristics, descriptors). The combination of identities and features or cognitive self-appraisals which occur at the intrapersonal level, enhance identity complexity by: creating rationales for their condition, creating hierarchies (ascribing to higher perceived socially valued identities), gaining understanding over time and experiences, and developing an empowered 'disability identity.'

At the extra-personal level (external to self; in relation to familiar and unfamiliar others), there is a task which IWDD negotiate related to 'how others see them' in various community environments. With known others, the reaction to those relationships is positively valenced as IWDD refer to being seen with respect, with understanding, and



with appreciation. With unknown others, participants have a sense of being socially ostracized due to having a visible disability.

Participants refer to others ‘seeing the wheelchair’ which situates IWDD as different from people without disabilities in society. Participants understand that when unknown others gain familiarity with them, social barriers related to misperceptions and stereotypes can be broken down. When IWDD cope with their condition, this reflects a *Response* which may be adaptive (Resiliency) or problematic (Pain/Despair).

*Response* may entail maintaining positively valenced features related to complex identities within one’s self-concept, and this in turn indicates adaptive coping. For example, exposure to and participation in a facilitated arts program may be an antecedent to the development of an ‘artist identity,’ a valued identity that then allows the IWDD to have the *Response* of feeling included in the greater community of artists, enhancing a sense of resiliency. In contrast, the absence of any valued additional identities may leave IWDD vulnerable to the *Response* of pain and despair as they are unable to gain validation from others, or even themselves. For example, the artist identity may become part of the multiple identities a person holds within their self-concept and can add to an individual’s identity complexity. The artist identity, for those who are drawn towards that type of activity, is associated with positively valenced features such as ‘accomplished, talented, and admired.’

This *Response* is *Reconciled*, a reaction which is reinforced through the enactment (*Reconciliation*) of varied identities. An adaptive example of this is when IWDD who are artists display their creations in galleries. In addition, some may sell their art which provides them with a sense of productivity. Further, some artists gain the admiration of

others which provides the artist with a sense of acceptance and belonging. As one artist stated “when they see the artwork on display, they don’t see the wheelchair.” This type of recognition adds to identity complexity (myself as a valued artist) which feeds back on IWDD’s cognitive self-appraisals (*Recognition*), or how they see themselves in relation to how others see them. In addition to widely acknowledged valued identities such as being an artist, or a mentor or a role model, some IWDD in this sample enact their disability identity by becoming advocates and gain benefits or ‘perks’ from their disabled status. This seems to facilitate resiliency and coping and a sense of inclusion/belonging in various social environments.

Failure to achieve an adaptive *Reconciliation* results in participants withdrawing or isolating from the wider communities. Some react by adopting what I term a ‘resigned acceptance’ or a resignation leading to apathy and stagnation. For example, according to caregivers, many IWDD will not complain or indicate any discomfort with their assistive technologies such as their wheelchair seating. They have resigned themselves to accepting their situation at the expense of obtaining greater comfort and sense of well-being. However, when evaluated at the clinic and provided with the proper communication strategies to allow effective communication, they will admit that there are problems with their assistive devices which simple adjustments may ameliorate.

### **Analytical Considerations**

The Principles of Normalization (Wolfensberger, 1983) sparked an international mission towards embracing the concept of ‘normalizing’ the life experiences of individuals’ with disabilities. This is extended with Social Role Valorization’s (Osborn, 2006) emphasis on IWDD’s rights to ‘the good things in life.’ The Americans with

Disabilities Act (ADA, 1990) pronounces that accommodations must be made for individuals with disability to access their communities, work, contribute to society and participate freely in activities of their own choosing. However, while superficially appearing to be noble endeavors, we may need to step back and evaluate what the enactment of these accommodations means for the very individuals they are meant to empower and whose lives they are meant to enhance. First let us consider the conceptualization of ‘being normal’ and the initiative towards normalization.

**Being normal.** Participants in this study spoke at length about ‘being seen as normal’ by typical people. They are poignantly aware of ‘being different’ and feeling that others stare and make assumptions based upon preconceived stereotypes which stigmatize people with visible physical disabilities (i.e. ‘seeing the wheelchair’). However, when asked what they would change about themselves if they could, very few (only Maury and Grace for example) stated that they would give up their disabilities and that they did not like being disabled. Most reflected on problems with access and the need to be dependent on others as problematic issues, but with resolution of those issues, having disability is ‘normal’ for them. They know of no other life.

Some participants react to the pressure to “be normal” by seeking to achieve unrealistic goals in the pursuit of normality and social acceptance by others, much like Jaleel’s unrealistic goal for going to a four year academic college (see chapter 6 Recognition). Jaleel has no specific career goal in mind, nor is he interested in learning about any particular subject. The impression I had from his interview was that he was bowing to social pressure to conform to what he perceived as the ‘normal’ trajectory for a young man his age. Not being able to achieve this dream has created frustration, anger

and depression for Jaleel. Redefining goals seems to be perceived by him as a failure.

The question that needs to be considered here is how we are socializing IWDD to strive to achieve some preconceived idea of ‘normality’ rather than emphasizing individual strengths and realistic, achievable goals.

I propose that the notion of ‘normalization’ implies a false construction because every person retains abilities which are uniquely ‘normal’ for that person. The Principals of Normalization focuses on access to the community and provision of physical accommodations. However, on an interpersonal level, achieving normalization with regard to social engagement in the community is still a struggle for those with physical, intellectual and communication disabilities. The conceptualization of the normalization principle as a foundation to promote inclusion has been questioned in the literature (Culham & Nind, 2003). IWDD continue to struggle with obtaining meaningful employment and social integration (Certo, Lueking, Murphy, Brown, Courey & Belanger, 2008; Wehman, 2003). The ability to contribute valued skills to a community is part of what makes any individual, IWDD included, feel productive and achieve a sense of wellbeing. These data allow exploration of the meaning of inclusion for IWDD in wider communities from their own perspectives.

**When inclusion becomes exclusion.** The goals for participants in this study are ‘acceptance by others’ and ‘being with their families and friends.’ The core concept of the theory generated from the findings in this study is: Acceptance/integration vs isolation/loneliness. Participants are social and want to be with their families and friends engaging in a wide range of activities and experiences which they find pleasurable. Most want to work or be productive in some way (e.g. being an artist, volunteer, adult program

attendee). Being productive, feeling efficacious, and nurturing and engaging in close social connections with family and friends are the goals for life quality as expressed by participants in this study.

What is the implication here regarding community inclusion? When reflecting on experiences out in the general community, many respondents expressed discomfort. They had a sense of being stereotyped and ostracized which contributed to feeling angry and depressed. IWDD typically either withdrew by avoiding such social exposures, or became loudly combative and hostile, perhaps perpetuating preconceived myths and stereotypes among the general population that IWDD have limited ability to regulate their emotions and behaviors.

The goal of inclusion in public policy initiatives has been poorly defined and suffers from a lack of conceptual clarity with regards to the outcomes it seeks to achieve (Culham & Nind, 2003); confusion exists over how communities and programs should implement integration of the IWDD population (Clement & Bigby, 2009). The inclusion initiative springs out of a U.S. Supreme Court ruling over discrimination against people with mental impairments i.e. *Olmstead vs L.C.* (1999). The Supreme Court adopted the position that individuals with mental disability have the right to live in their communities rather than be confined to a mental institution. This ruling set further precedents for housing, education and community integration of IWDD.

The movement towards deinstitutionalization arose from an emerging awareness of the abuse and neglect of people with disabilities residing in large institutionalized settings. These settings were legally ruled as unconstitutional in the 1970s. The rationale underlying those court rulings is that those individuals assessed to not be of danger to

themselves or others should not be forcibly detained in such living environments against their will. Individuals with cognitive impairments, who were not in need of a skilled level of nursing care, should be reintegrated into the general community (Lakin, Prouty, Polister, & Coucouvanis, 2003). In keeping with the tenets of the American with Disabilities Act (ADA), the Supreme Court ruled that it was unconstitutional to house IWDD in institutions in lieu of community based settings (*Olmstead v L.C.*, 1999). The ruling states:

Specifically, we confront the question whether the proscription of discrimination may require placement of individuals with developmental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes. Such action is in order when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities...(*L.C. & E.W. vs. Olmstead*, p. 588)

This Supreme Court decision equated the practice of institutionalization of IWDD with discrimination and segregation which disregards the ADA's intent towards integration of IWDD into the general community. While well-intended, this rather over-reaching interpretation of the ruling fails to take into account individual differences of individuals with disability. While some may have the ability to successfully integrate into their wider communities, IWDD who have multiple, complex and profound conditions may not be best served under this initiative. The process of erecting a solitary

group home within a social community of individuals without disability may isolate those group home individuals with disabilities. According to research by Alphen, Dijker, van den Borne and Curfs (2009), neighborhood contact of IWDD is not associated with a sense of belonging. Living in the community creates experiences with their neighbors, a process they term ‘neighboring.’ Participants in that study appreciated the greater freedom to explore their environments and autonomy to create their own schedules much more than having the opportunity to interact with their neighbors. Those interactions, when they do occur, are described as superficial and laced with apprehension by the participants.

When IWDD are placed in isolated community group homes, they are separated from those who *want* to socially interact with them, like those familiar others from the medical and educational center (MEC) who they view as surrogate family members. In addition, for those with communication impairments, lack of additional oversight and respite for caregivers from additional staffing resources may portend issues for quality of care outcomes and burn-out of caregivers (Gray & Muramatsu, 2013). Finally, when IWDD are living in communities of others dealing with similar levels of disability, in communities that are specially designed to accommodate mobility and communication impairments, they can actually “feel normal” because their experience *is* the norm.

***Intentional communities.*** Contrary to current initiatives for de-institutionalization and desegregation, I do not perceive solitary group home units erected within the context of a community township as facilitating social integration of the IWDD population in the social community. The results from this research project lead us to question our perceptions of inclusion, and ask ‘when does inclusion become

exclusion?’ We, in effect, are doing the opposite of what we intend by deinstitutionalizing IWDD into isolated community group homes or supervised apartments. Social interactions with unknown others who are unfamiliar with disability may be impeded by basic social communication and relationship issues. Understanding, areas of common interest, and mutuality of shared goals define social relationships for many (Brown, Ouellette-Kuntz, Lysaght, & Burge, 2011; Walton et al., 2012). It takes time, effort and a sincere interest in creating social bonds with IWDD for unknown others to expend the energy and resources necessary to build these types of relationships. They just may not have, nor want to have, the motivation to expend this energy.

Intentional communities (Randell & Cumella, 2009) make intuitive sense in enhancing IWDD’s life quality and self-concept. Intentional communities are small networks of housing for individuals with disabilities grouped in a village-type community. Intentional communities were originally created in England in response to hospital closure programs. Residents of this type of community manifest benefits such as engagement in meaningful employment and development of a positive sense of community (Randell & Cumella, 2009). Such a housing model could save money, foster administrative ease, enhance a sense of family/social opportunities, and decrease IWDD’s sense of isolation and stigma (Cummins & Lau, 2003).

By living with and near others with disability, IWDD have a built-in 'neighborhood' with potential for wider neighborhood engagement. The parent organization would save money on nursing and caregiver expenses (Randell & Cumella, 2009). There could be a community store run by the 'neighbors,' along with opportunities for the greater community to interact with IWDD on a larger scale. Other research



supports this conclusion that a sense of belonging or connectedness to a community is facilitated by interactions within communities of IWDD (Cummins & Lau, 2003).

Being in a community with people sharing 'lateral identities' with all the necessary accommodations would resolve this issue. Lateral identities are those identities shared with others with similar attributes/characteristics (Solomon, 2011). For example, individuals in wheelchairs may maintain a lateral identity with others in wheelchairs (as opposed to vertical identities found within biological relationships i.e. having brown skin, blond hair, or blue eyes. There would be potential for social integration into wider community environments. To further expand on this notion, IWDD who are neighbors could be invited to social events, become increasingly familiar to unknown others who are non-disabled, so when residents with disabilities venture out into the wider community, they would be known and not so ostracized. In intentional communities, I believe there would be less caregiver burnout and increased integration. Randell and Cummella (2009) compare this type of community with residential campuses and staffed homes which are dispersed throughout communities and found that those IWDD who resided in intentional communities were more frequently involved in community planning, were safer, better cared for and had better staff support.

This type of community is frequently seen in communities of foreign immigrants. New immigrants to a foreign country usually live grouped together in like-communities. They share language, shopping preferences and religious worship sites. As with minority immigrants, there is future potential for full integration. Ghettoization is associated with negative connotations but there are benefits for living with others (of similar cultural backgrounds) who want to socially engage with each other in a

community based setting. Randell and Cummella (2009) note that some might criticize intentional communities as being contrary to the Principal of Normalization and as a return to segregation of IWD. However, they argue that such communities provide a better life quality and a springboard for community involvement as stated above.

When IWDD venture into typical communities, they often perceive ostracism; they may respond with anger which then sets up a situation in which they experience more negative judgments from typical community members and this vicious cycle can be ongoing. Instead, intentional communities provide a chance to be known (through educating others, collaborating on mutual projects, working in the community) that can create bridges of understanding.

Intentional communities provide an environment where IWDD are more likely to encounter others, people willing to take the time and effort to truly socially engage with them. This rationale may ring especially true for those with intellectual disabilities. Individuals with physical disabilities often face environmental barriers and social exclusion based on misperceptions and erroneous attributions. However, individuals with cognitive impairments face social barriers leading to social exclusionary processes based on lack of common interests and areas of engagement (Deutsch, 2011). What might be indicated for this population is to redefine goals with respect to community integration. According to current policy initiatives underlying the American with Disabilities Act for de-institutionalization, this consists of erecting a domicile of IWDD in a typical neighborhood. The inherent assumption here is that the more IWDD experience physical integration, the better their lives will be. The physical integration component may be easier to achieve, the social integration remains elusive.

Although recent political initiatives to fully integrate IWDD into communities at large had good motives, legislators need to consider the social and behavioral implications for IWDD. Gaining social acceptability is not just a matter of situating a person into a particular social context, as anyone of a minority race/ethnicity can readily attest. Care and planning must be directed towards creating environments that are socially accepting; it is not merely a matter of access and proximity as adherents of NIMBY (Not In My Back Yard) might agree. Communities must be developed where IWDD can feel a sense of belonging and attachment in order for them to feel normal and included. Hall (2010) suggests that artistic spaces might provide one such venue.

**Being an artist.** Hall (2010) unravels the differences between the intent towards ‘social inclusion’ in social policy initiatives and the ‘sense of belonging’ that really references a quality of life experience for IWDD. Social inclusion does not necessarily cause IWDD to feel a sense of belonging in a particular environment. Social inclusion is a concept policy-makers use as a guideline for enacting policies for community integration. Hall (2010) suggests an arts environment provides IWDD with a sense of belonging and creates a bridge towards enabling wider community acceptance/integration.

Data within Chapter 6 indicate how ‘Being an Artist’ offer participants the opportunity to engage with others in community settings. IWDD become productive (produce and sometimes sell artwork), are admired by gallery visitors, and are perceived as ‘an artist’ rather than as someone with a negative trait such as having disability. This process is what Hall dubs ‘social reinscription’ (p. 86). As discussed in Chapter 4 (Recognition), this process falls under the cognitive self-appraisal of hierarchy.

Participants who are artists are able to ascribe to a higher social category or valued identity (or role). As previously discussed (and a component of STOIC), there may be protective value in associating with highly regarded social categories. Being an artist engenders pride of accomplishment and bridges a path towards positive community interactions with unknown others (Stickley, Crosbie, & Hui, 2011).

HICLAS analytic structures reinforce the above conclusions of the impact of the artist identity as an antecedent of identity complexity for IWDD in this study. HICLAS analytic structures manifest, for those who participate with the arts, the ‘artist identity’ high up within their structural hierarchy, adding to its complexity. Those artist identities are associated with positively valenced features indicating that this part of the IWDD’s self-concept is positive for the individual and yields positive cognitive self-appraisals (according to the STOIC framework).

**Being disabled.** Data from this study indicate that enacting one’s disability identity and becoming part of one’s community with others who are disabled inspires a sense of inclusion and belonging. While a few seek to disassociate from their MEC peers, most enjoy and value those relationships and feel a sense of community as suggested by the construct of ‘my MEC family.’ Owning one’s identity as a person with disabilities is not overtly recognized by many in this study but emerges at the top of every participant’s identity structure from the HICLAS analytical process.

As previously discussed, ‘being disabled’ is normal for participants. They have no experience of being non-disabled as do those with acquired disability. This means their disability is an inherent part of their self-concept. People in this study seem to accept this aspect of their self-concept and adopt different ways of reconciling their

disability identity. While becoming a disability advocate and a “voice for the voiceless” as Henry proclaims himself to be, seems to be a positive role for some, deemphasizing this aspect in favor of other social roles and avocations is another manner of reconciling their disability identity. As Maury articulates, “I don’t focus on being disabled... I don’t like being disabled,” some choose to focus on more positively perceived identities within their self-concept.

### **Conclusions**

Limited research exists investigating impacts of enriching environments on identity complexity and enhancement of self-concept and ultimately on life quality for IWDD. Through understanding these processes, social work practice can be enhanced and interventions can be created ensuring exposure and integration for IWDD in a variety of enriching environments.

As IWDD build role complexity, they build self-confidence, and they may venture into wider communities where they may challenge preconceived stereotypes. This may or may not coincide with developing self-advocacy or community advocacy groups. Through feeling an enhanced sense of inclusion and belongingness, IWDD may filter into larger social communities and be exposed to varied social contexts. Through exposure to various contexts and developing identity complexity, IWDD may take on new roles and become producers, contributing to society and enhancing their inherent value in the eyes of ‘others’ thereby breaking down preconceived stereotypes. Exploding developments in technology have created opportunities for involvement in social contexts in an unprecedented manner. The impact of the technological revolution inspires such

integration but also creates new and complicated challenges to be negotiated when implementing these technological imperatives.

**Assistive technology (AT).** The Social Model of Disability precipitates Social Role Valorization's emphasis on modifications in the environment to afford access to IWDD so they may fully interact in everyday society. AT and other accommodations may allow easier involvement and integration for IWDD (McNaughton & Bryen, 2007). Information technology, computerized voice output devices and motorized wheelchairs provide opportunities for participation in many previously unforeseen arenas. While of unprecedented benefit in facilitating access and enhancement of quality of life for IWDD, there are many issues which need to be identified and addressed for AT to be of maximum benefit for IWDD.

***Adaptive assistive technology: communication.*** A careful balance must be maintained in using AT which can be viewed by IWDD as both a help and a hindrance. For example, a voice communicator device can be both an advantage in facilitating communication, but also perceived as ostracizing and alienating. Some devices have artificial voices which sound tinny, childlike, or robotic. Many young adults and adolescents are put off by the sound of these devices and would prefer not to use them. Some individuals prefer to use communication boards, switches, sign language or their own vocalizations which may be difficult for unknown others to understand but understandable to known others. IWDD's own choice and self-determination is a crucial element in determining whether an AT is the right option for an individual (Cook, 2009; van der Meer, Sigafoos, O'Reilly, & Lancioni, 2011). In addition, family, caregivers and

staff buy-in becomes a huge component in determining whether the individual is motivated, supported or dissuaded from using the device (Hammel, 2003).

***Adaptive assistive technology: wheelchairs.*** Another example of AT's benefits and drawbacks is the iconic symbol of disability, the wheelchair. A properly designed wheelchair specific for an IWDD's needs can support positioning preventing, delaying or decreasing respiratory conditions, postural issues, pressure sores, drooling/swallowing issues and overall health and social acceptability. Motorized wheelchairs enable individuals with severe cerebral palsy to independently navigate their environments enhancing their self-efficacy in accomplishing their goals. However, despite the fact that a wheelchair will get people where they want to go, it is also ostracizing when others "see the wheelchair."

There are also ethical problems when AT devices require maintenance when insurance no longer covers the device. If the AT device is not upgraded regularly, or repaired when damaged, then it can be unsafe and of no use for the individual. In addition, failure to pay careful attention to maintenance issues can exacerbate social undesirability of the individual rather than increase their ability to engage in social interactions (Cook, 2009). For example, improper positioning in a wheelchair can impact an IWDD's posture, exacerbate drooling, impact their respiration (breathing), and hamper one's ability to self-propel and negotiate environments effectively, safely and independently. Each AT has benefits and drawbacks that require IWDD and their supporters to continually assess the balance among them (Dorsten, Sifford, Bharucha, Mecca, & Wactlar, 2009).

**Practical implications for social work.** Clinical implications from this study for social workers include the need to assure that IWDD have opportunities to explore different roles, activities and communities. These opportunities may help them affiliate with those that allow them to feel productive, included and of worth in order to achieve higher perceived hierarchical self-concepts. Social workers can encourage ‘hierarchy’ i.e. for IWDD to develop higher perceived (more valued) social roles such as being an artist or an advocate. In addition, creating roles with positive associations in higher categories may add to IWDD’s identity complexity and provide them with a buffer to trauma and loss (Linville, 1985, 1987). A facilitated arts program provides IWDD with an opportunity identify within the social category of artists; this promotes feelings of productivity, integration and self-expression. In addition, social workers can seek to increase opportunities for IWDD to engage in the community through work opportunities, volunteer, sports, and community action projects. Finally, social workers should assist IWDD to reframe goals keeping with person-centered philosophy which stipulates that focus should be placed on the individual needs and preferences of the person served.

Social work practitioners are in a prime position to affect changes in society’s perceptions and attitudes towards IWDD. “Person-centered planning,” personal development (empowerment and self-determination), user-friendly and person-first language (Blaska, 1991), and prosthetics and technology (Schalock et al., 2002) foci have jettisoned the field into new domains. This propulsion enhances the ability of clinicians to communicate with previously nonverbal clients and allows clients to access and interact in previously unobtainable (inaccessible) domains/environments.



In essence, these developments heralded changing perceptions of the population. Changing perceptions may erode barriers which in turn may allow IWDD access to experiences that enhance their quality of life and open educational, vocational and recreational possibilities which might otherwise be prevented due to physical/environmental barriers (Brown, 2009). A review on historical perceptions of disability concludes “Societal attitudes are significant since they determine to a large degree the extent to which the personal, social, educational and psychological needs of persons with disabilities will be realized” (Wa Munyi, 2012).

Social workers may become strong advocates for the IWDD population providing the linkages among programs, families and services embedded within an individual’s personal journey. Acknowledging self-determination and human rights in underserved populations guides social work’s professional mission. Interpreting, understanding, and giving voice to vulnerable populations is central to social work’s dedication to social justice issues in general, and of critical consequence and benefit to individuals with disabilities in particular. Results from this study provide insight into the development of self-concepts in individuals with multiple disabilities, and highlight their aspirations to be part of their communities. Furthermore, these results may inform practitioners about interventions for enhancing life quality and facilitating self-determination in individuals with multiple disabilities.

***Policy Implications.*** The Social Model of Disability explains how accommodations can facilitate IWDD to more easily fit into different communities and social situations. The time has come to implement these accommodations in ways that promote mutually respectful communications among IWDD and typical community

members. Intentional communities and communities of affiliation such as artists may promote steps in more inclusive directions.

This study indicates that creating opportunities for IWDD to be successfully integrated in social systems is important for IWDD's sense of well-being. Developing bridges that IWDD can traverse while adopting valued identities such as 'an artist,' 'a volunteer,' 'a fellow work employee,' may be one pathway by which unfamiliar others become familiar and IWDD feel that they belong. Similarly, slowly integrating living communities of IWDD by creating intentional communities may provide additional opportunities for wider community integration while maintaining valued social relationships and a sense of belonging.

Implications on a policy level would include: a) an exploration into the value of intentional communities as a bridge to traverse the social gap between IWDD and others in their communities; b) reconsideration of 'least restrictive environments' and 'community integration' as goals viewed to be of inherent worth; and c) recognize IWDD's desire for achieving 'normalization' within their own contexts, rather than assuming that it is best found among typical communities. Policies need to be developed with an understanding of IWDD's goals rather than policy-makers decisions to push inclusion at the cost of stigmatization and re-inscription of disability.

***Limitations and future research implications.*** The strength of qualitative research is in gaining a rich understanding of a unique population of interest. Due to this sample's specific diagnoses, information from this study seems to reflect the needs/desires of adults with spina bifida, Lesch-Nyhan disease and cerebral palsy. However, it is likely that individuals with: Dementia/Alzheimers' Disease, veterans with disabiliites,

and individuals diagnosed with other forms of mental illness, may experience similar needs for engagement in valued activities. In addition relocation to intentional communities should be explored as an alternative which allows for a middle ground before IWD are thrust into typical communities where stigma and dis-abling conditions may exist. Further research with larger sample sizes and varied demographics and diagnoses will be useful in exploring these questions. Triangulation with quality of life surveys, self-esteem assessments, depression inventories and anxiety scales would further validate findings. Focus groups may provide additional rigor.

Despite the challenges of incorporating IWDD into research projects, an implication derived from the current study is that there is a need to create methods whereby this population can fully participate and have their voices heard in both qualitative and quantitative research protocols. A paper published from the data in this study noted that IWDD who participated in research enjoyed the experience, felt productive, and appreciated the opportunity to tell their story despite various research conundrums encountered during the consent/assent and data gathering processes (Wilkenfeld, 2014). Those conundrums consist of obtaining consent which involves gaining access to participants as some parent/guardians become gatekeepers for those who need their guardian's consent. Guardians may prevent participation for some who may wish to participate, under the guise of protecting their child from stress. Another consent/assent issue surrounds the need to be cognizant of the potential for coercion in this population who are vulnerable and acquiesce due to social desirability tendencies. Secondly, communication dilemmas stem from both expressive language issues due to physical disability and receptive language issues related to lower intellectual ability to

comprehend the survey questions by some of the participants. In addition, role confusion issues may arise when a clinician operates under the guise of a researcher in a practice setting.

Findings from this study lead to the conclusion that there is much to be gained by listening directly to IWDD. Attending to barriers with marginalized populations may facilitate exploration into the lived experience of IWDD thus providing opportunity to obtain rich information and to enact the social justice mission of social work with IWDD (Wilkenfeld, 2014). The IWDD at the MEC approached me regularly wanting to be informed of the findings, participate in member-checking, and be kept updated on the progress I was making towards completion. Further, as reported in the findings, ‘participating in research’ may be another social role for IWDD that creates an additional valued identity to add to their self-concepts.

### **Concluding Summary**

This project set out to investigate how IWDD make meaning of their lives, the types of contextual environments which provide them with life quality and the processes through which exposure to and involvement in varied and enriched social environments impact identity complexity and ultimately their self-concepts. Findings indicate three overarching processes at work; Recognition (cognitive level), Response (emotional level) and Reconciliation (behavioral level) all of which act at varying levels of distance from self (intrapersonal, extra-personal: known others, extra-personal: unknown others). These processes are reflexive as each impacts the other as indicated in Figure 4 and create the underlying foundational rationale for STOIC (the Social Theory Of Identity Complexity).

Participants adopt various strategies to achieve a sense of well-being. Some seek to elevate their social status by a process I term ‘hierarchy’ i.e. assuming higher perceived valued identities such as a mentor, educator, advocate or an artist (which enhances their identity complexity and ultimately self-concepts). Most of the participants work to reinforce relationships with familiar others such as family and friends. Some also elevate their disability identity to a higher social category through networking with others with disabilities, advocating for rights and wearing their ‘disability identity’ with pride as indicated in their disability advocacy work or as exhibited in their artwork, writings and other artistic representations. By enacting these various strategies (Reconciliation), participants may exhibit resiliency and subsequently achieve a sense of well-being (Response) which feeds back on how they think about themselves (Recognition).

Achievement of community integration needs to be re-conceptualized with the goals and objectives of IWDD from a person-centered lens. As seen from the results of this project, IWDD develop social ties and familial connections with those with whom they live, work and interact during the course of their everyday lives. Inventing opportunities for IWDD to create these connections with the larger community is the challenge for successful integration to be realized. Social inclusion is not merely a matter of situating a person in a social environment without preparation of the social community and development of community initiatives to promote inclusion. These bridges of integration can be navigated through development of shared goals working towards the betterment of the community at large while maintaining and reinforcing valued social connections within their communities of ‘known others’.

## Chapter 9. References

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## APPENDIX 1.

Approved by Rutgers University Internal Review Board and the Institutional Review Board for the organization that provides residential and day program services for the participants.

### **Qualitative Interview Guide:** (Flexible and narrative format)

#### **Participant's Perception of Life Quality**

1. Begin with 'grand tour' opening question: When you think about yourself, what things do you like most about yourself and what things would you wish you could change?

#### **Experience of Disability**

1. *Could you please describe some of the ways in which your day-to-day life has been affected by your disability?*

Prompts:

How so?

Can you give me an example?

2. *What are the positive aspects of having a disability? What are the negative aspects?*
4. *Describe the biggest obstacles that face you with your disability.*
5. *Has the experience of having a disability become an important part of how you see your self?*

#### **Self-perceptions related to important aspects of my life**

6. *What are some positive aspects of your life generally? Negative aspects?*
7. *If you could change your life in any way, what would you change?*
8. *The most important thing to me is...?*
9. *The best way I have to express myself is...?*

10. *Important relationships to me include...*

11. *Please identify some activities that you are involved with that have a strong impact on your life.*

12. *How would you describe your romantic life? What would you wish it to be?*

13. *How would you describe your sexual life?*

14. *Please identify any other aspects of your life not already mentioned that are important to you.*

**Self-perceptions related to the arts (for participants in the Arts Access Program)**

15. *How did your interest in the arts begin? What were the most important influences?*

16. *What forms of artwork give you the most satisfaction? Can you describe what is satisfying about creative activity?*

17. *How does your work express your feelings? Has this changed over time?*

18. *What themes do you express in your artwork?*

19. *What are your future plans with regards to your artwork?*

20. *Is being an 'artist' an important part of your self-image?*

21. *In what ways has being an artist helped you to manage/live with your disabilities?*

22. *Tell me about this particular piece of artwork. What is its meaning for you?*

**Conclusion**

Is there anything else you would like to add? Is there anything that you think I should understand about your experience with [insert diagnosis]?



## APPENDIX II.

## Identity Assessment Method

## PART I

## PEOPLE IN YOUR LIFE

## RATINGS

Imp.

- |  |       |       |       |
|--|-------|-------|-------|
| 1. Mother (if not raised by biological mother, name the _____<br>Person who you regard as “mother”).   | _____ | _____ | _____ |
| 2. Father (if not raised by biological father, name the _____<br>Person who you regard as “father”).   | _____ | _____ | _____ |
| 3. Most liked sibling (if none or only one, write _____<br>“none” or “one only” under the space provided<br>for the name). Or sibling you feel closest to. | _____ | _____ | _____ |
| 4. Least liked sibling, or sibling you feel least close to. _____  | _____ | _____ | _____ |
| 5. A casual friend you have now. _____   | _____ | _____ | _____ |
| 6. Another casual friend you now have. _____   | _____ | _____ | _____ |
| 7. Your best friend now. _____   | _____ | _____ | _____ |
| 8. Significant other. _____  | _____ | _____ | _____ |
| 9. Most liked other relative (uncle, aunt, cousin, etc.) _____   | _____ | _____ | _____ |
| 10. Most disliked other relative. _____  | _____ | _____ | _____ |
| 11. Most liked supervisor (or coworker). _____   | _____ | _____ | _____ |
| 12. Least liked supervisor or coworker _____   | _____ | _____ | _____ |
| 13. Most liked teacher/therapist/nurse. _____  | _____ | _____ | _____ |

- |   |       |       |       |
|---|-------|-------|-------|
| 14. Least liked teacher/therapist/nurse.          | _____ | _____ | _____ |
| 15. Current or most recent employer or teacher    | _____ | _____ | _____ |
| 16. Most disliked person in your life now         | _____ | _____ | _____ |
| 17. Most admired person in your life now.         | _____ | _____ | _____ |
| 18. Four other important people in your life now, | _____ | _____ | _____ |
| 2 liked and 2 disliked, that you haven't already  | _____ | _____ | _____ |
| mentioned.  | _____ | _____ | _____ |

## APPENDIX III.

## Identity Assessment Method

## PART II

## SOME ASPECTS OF YOUR LIFE

## RATINGS

Imp.

19. What is your present job? If unemployed or in school

List your grade.

\_\_\_\_\_

20. If in the past you had a different job, what was it?

\_\_\_\_\_

21. What are your main ambitions now? List up to two.

\_\_\_\_\_

Which of the two might you choose if you had to let

one go?

\_\_\_\_\_

22. What groups, clubs or societies do you belong to

\_\_\_\_\_

at this time?

\_\_\_\_\_

23. What are your current hobbies or interests and

\_\_\_\_\_

recreational activities?

\_\_\_\_\_

24. Are there any diseases, physical handicaps, or

\_\_\_\_\_

special physical conditions that you may have

\_\_\_\_\_

(even if under control at this time) that have

\_\_\_\_\_

made a difference in your life?

\_\_\_\_\_

25. What habits do you have and want to get rid of

\_\_\_\_\_

but can't seem to?

\_\_\_\_\_

26. What recurring thoughts or feelings do you have \_\_\_\_\_  
 and want to get rid of but can't seem to? \_\_\_\_\_
27. What is your current religious orientation? \_\_\_\_\_
28. If different from above, what has been your  
 religious orientation for most of your life? \_\_\_\_\_
29. What is your sexual orientation? \_\_\_\_\_
30. What is your ethnic background? Include race,  
 If that is an important aspect of your identity. \_\_\_\_\_
31. List up to two other aspects of yourself or your  
 activities that make a difference in your life \_\_\_\_\_  
 and that you have not as yet mentioned? \_\_\_\_\_
32. Rate self as a Matheny resident \_\_\_\_\_
33. Rate self as a member of the community \_\_\_\_\_

APPENDIX IV.  
RATING FORM- PART III

Participant #: \_\_\_\_\_

Bring your attention completely to yourself in the situation indicated in the sentence below:

When I am \_\_\_\_\_ (with my friends as an example) I am:

Respond with a “yes”, “no”, or “somewhat” to these descriptions. Answer “yes” if the description applies to you most of the time in the situation. Answer “no” if the description almost never applies to you in this situation. Answer “no” if the description never applies to you in the situation. Answer “somewhat” if the description applies to you somewhat or some of the time in this situation.

Remember we are interested in how you see yourself when you are \_\_\_\_\_

Rate as 0 or 1      *{Feature vocabulary list (developed from descriptors that participant used in describing himself in relation to various people and aspects of his/her life)}*  
(indicates      *presence or*      *absence of*      *feature in relation*  
to the above identity.

_____	happy	<i>(examples of descriptors a participant might come up with; the idea for participant to create a list of at least 30 such descriptors)</i>
_____	sad	
_____	energetic	
_____	admired	