

ENGAGEMENT OF STUDENTS WITH INTELLECTUAL AND DEVELOPMENTAL
DISABILITIES IN POSTSECONDARY EDUCATION

Emily Beth Furgang

A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill
in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the
Division of Occupational Science

Chapel Hill
2013

Approved by:

Ruth Humphry, PhD, OTR/L

Nancy Bagatell, PhD, OTR/L

Brian Boyd, PhD

Virginia Dickie PhD, OTR/L

Dorothy Holland, PhD

© 2013
Emily Beth Furgang
ALL RIGHTS RESERVED

ABSTRACT

EMILY BETH FURGANG: Engagement of Students with Intellectual and
Developmental Disabilities in Postsecondary Education
(Under the direction of Ruth Humphry, PhD, OTR/L)

This dissertation presents findings from an ethnographic study of students with intellectual and developmental disabilities (IDD) enrolled in a specialized postsecondary education program at a public university in North Carolina. Specifically, it discusses how 10 students engaged in postsecondary education activities and developed student identities over the course of one academic year. A transactional perspective is used to frame this study holistically, such that the transactions of various factors contributing to the students' occupation and identity development are considered. This research is significant for occupational science because it examines a period of transition that is influential in shaping current and future life occupations. Moreover, it explores the novel occupational experiences of a population that has historically been restricted from engaging in postsecondary education.

This study utilized qualitative methods, including semi-structured interviews and participant observation with college students with IDD. Findings address the transactional nature of engagement in postsecondary education and the construction of the students' occupations and identities, while affirming the dialectical relationship of occupation and identity previously described in the occupational science literature. These

findings are portrayed through stories of the students' experiences. Further areas for research related to the experiences of college students with IDD engaging in postsecondary education are also discussed.

ACKNOWLEDGEMENTS

I am thankful to Dr. Angela Rosenberg for her professional mentorship during my fellowship at the Carolina Institute for Developmental Disabilities (CIDD), as well as her personal mentorship as I completed my dissertation. My gratitude is extended to Donna Yerby and Deborah Zuver of the CIDD for bringing me into the world of postsecondary education for students with intellectual and developmental disabilities.

I am especially indebted to the students, staff and alumni of the Making Strides program for welcoming me into their lives to conduct this research. I am especially grateful for their wiliness to share their experiences with me.

Finally, completion of this project would not have been possible without the endless support, guidance and encouragement of my fiancé, Michael Kertcher, and my parents, Nancie Furgang and Stuart Furgang. Thank you for reminding me that I could actually accomplish this tremendous feat. I love you.

TABLE OF CONTENTS

Chapter

| | |
|---|----|
| 1. INTRODUCTION..... | 1 |
| Philosophical Approach | 4 |
| Chapter Descriptions..... | 4 |
| 2. BACKGROUND..... | 6 |
| Introduction..... | 6 |
| Postsecondary Education..... | 7 |
| State of the Literature of Postsecondary Education for Students with IDD..... | 13 |
| Identity..... | 17 |
| Identity and Occupation..... | 19 |
| Conclusion..... | 23 |
| 3. POSITIONALITY..... | 25 |
| Personal Background..... | 25 |
| Developing a Focus: An Iterative Process..... | 27 |
| Researcher as Participant..... | 30 |
| Methodological Developments..... | 32 |
| 4. PILOT STUDY: KENDRA..... | 34 |
| Identity and Occupational Engagement..... | 36 |
| Accommodations versus Modifications..... | 41 |
| Expectations..... | 44 |

| | |
|--|----|
| Balancing Lives..... | 47 |
| Pilot Study Conclusions..... | 49 |
| 5. METHODOLOGY..... | 51 |
| Ethnography..... | 51 |
| Guiding Questions..... | 54 |
| Study Approval..... | 55 |
| Participant Criteria and Recruitment..... | 56 |
| Data Collection: Interviews..... | 57 |
| Data Collection: Participant Observation..... | 58 |
| Data Collection: Acquisition of Supplemental Programmatic Information..... | 59 |
| Data Analysis..... | 60 |
| The Study Location..... | 61 |
| Primary Participants..... | 63 |
| 6. MAKING STRIDES: A CLOSER EXAMINATION..... | 70 |
| History of Making Strides..... | 70 |
| Eligibility for the MS Program..... | 71 |
| Paying for MS..... | 72 |
| Academics..... | 72 |
| Student Supports..... | 74 |
| Student Housing..... | 75 |
| Student Identification Cards..... | 75 |
| Situating the Occupational Experience..... | 76 |
| Postsecondary Education for Students with IDD: A Figured World..... | 78 |

| | |
|--|-----|
| Enacting the Figured World of Postsecondary Education for Students with IDD: An Experience-Based Lexicon of MS..... | 81 |
| Conclusion..... | 87 |
| 7. STORIES OF INCLUSIVE (AND EXCLUSIVE) SUPPORT..... | 89 |
| Discussion..... | 93 |
| Support as Hierarchical or Shared Experiences..... | 93 |
| The Complexity of Inclusion..... | 98 |
| Conclusion..... | 101 |
| 8. STORIES OF BEING A COLLEGE STUDENT..... | 102 |
| Discussion..... | 106 |
| Doing Identity: The Dialectical Relationship of Identity and Occupation..... | 106 |
| Constructing Opportunities for Occupation and Identity Development..... | 108 |
| Rules: The Practical Application of Occupation and Identity..... | 109 |
| Conclusion..... | 115 |
| 9. CONCLUSION..... | 116 |
| Introduction..... | 116 |
| The Transactional Nature of Engagement in Postsecondary Education For Students with IDD..... | 116 |
| Occupation and Identity..... | 117 |
| Areas for Further Study..... | 118 |
| Contribution to Occupational Science and Related Fields..... | 119 |
| Limitations..... | 120 |
| A Personal Reflection..... | 120 |
| NOTES..... | 124 |

Appendices

| | |
|--------------------------------------|-----|
| A. DEFINITIONS..... | 128 |
| B. MS COURSE CATALOG..... | 130 |
| C. MS COURSE OF STUDY SCHEMATIC..... | 140 |
| D. DATA COLLECTION MATERIALS..... | 141 |
| REFERENCES..... | 145 |

Chapter 1

Introduction

[A college student is] someone who's taking classes on campus and they're living the teenage, typical life, about to be adult life, you know, young adult life, put it that way. (Sean, a freshman)

[A college student is] just somebody who attends college and runs through the courses, you know. It's just like they're out running an obstacle course, you know? It's like, you know, an athlete. Maybe you've got a bunch of hurdles you have to jump through—jump over before you graduate... And then all of a sudden you get over the last hurdle and voila! You graduated! (Benjamin, a junior)

College students from a large public university answered the question “What is a college student?” based on their own experiences. Sean, a late teen, illustrated college as a period of transition to adulthood. Benjamin, who had completed more than half of his college education, alluded to college as a series of challenges that eventually culminates in graduation. I can relate to both Benjamin and Sean when I think about my own college experience, and I imagine that others who have experienced college may feel similarly connected to these students. The experiences these young men refer to are very different from my own, however: they are being lived by students with intellectual and developmental disabilities (IDD).

Sean and Benjamin are two of nearly 30 students at a state university in North Carolina who are pioneering the world of postsecondary education for students with IDD. Through their participation in a program that will be referred to in this dissertation as Making Strides (MS), Sean, Benjamin, and their peers with IDD are taking classes on this college campus in order to earn a university-recognized certificate. The MS students attend core courses in the MS curriculum as well as electives in other degree programs. Many of them, including Sean and Benjamin, live in inclusive student housing located near the campus.

MS is a part of a state university that has educated students for more than 150 years but has only admitted post-high school students with IDD since 2005. The novelty of postsecondary education for students with IDD makes it relatively uncharted territory for educational systems and students, as well as researchers in occupational science. This dissertation is an attempt to explore that territory. I followed 10 students with IDD as they participated in the MS program during the 2011–12 academic year. Through interviews and observations, I explored these students' engagement in college activities not only in and out of classes but also on weekdays, weeknights and weekends. I went into their communities (campus and local city) and their homes.

Benjamin's definition of a college student sets the theoretical stage for this dissertation. Benjamin likened the college student to an athlete completing an obstacle course. Inherent in his answer, although not overtly mentioned, is the construction of the course. This dissertation will explore how that course is set: who sets it, its obstacles, and how the students navigate these challenges. In short, this dissertation explores the social construction of the student experience within the culture of the MS program. As other

researchers in occupational science and anthropology have argued strong cases for the dialectical relationship of activity and identity (Holland, Lachicotte, Skinner, & Cain, 1998; Huot & Laliberte Rudman, 2010; Laliberte-Rudman, 2002), I also explore the relationship of activity and identity (i.e., how jumping academic and social hurdles and feeling like an athlete are related).

What is missing from the theoretical discourse and academic literature on activity and identity in occupational science, however, is consideration of how the relationship of activity and identity unfolds for college students with IDD as they transition to adulthood. As Sean observed, college is a point of transition to “adult life”; postsecondary students with and without disabilities must navigate new ways of learning, socializing, and living, all while becoming members of an educational community and learning to become independent adults. This dissertation explores the relationship of activity and identity during this transitional process. Moreover, because postsecondary educational practices for American students with IDD are relatively new, this study addresses novel experiences of occupational engagement.

This research is significant for occupational science because it explores a period of occupational transition that is influential in shaping current and future life occupations. Specifically, it yields information about the relationship of occupation and identity for college students with IDD through the illumination of situational transactional relationships and reveals new insights about this relationship through the unfolding processes of engagement and transition. The potential applications of this research give this study translational value; therefore, I intend to share it with practitioners in the field of IDD to guide programmatic practices for college students with IDD.

Philosophical Approach

I employed a transactional perspective in the design and implementation of this study. The transactional perspective, developed by occupational scientists Malcolm Cutchin, Virginia Dickie, and Ruth Humphry (Cutchin & Dickie, 2012; Cutchin & Dickie, 2013; Dickie, Cutchin, & Humphry, 2006) from the University of North Carolina at Chapel Hill, is based on John Dewey's pragmatic philosophy. Through a transactional approach, people are understood as relating with their environments rather than as separate entities acting inside of their environments. Such relationships are shaped and reshaped as people transact with various environmental aspects. I used an ethnographic methodology because it allowed me to appreciate the various transactions of personal, social, cultural, and historical factors that shaped the participants' occupational situations. The coupling of the transactional perspective and an ethnographic methodology further facilitated my understanding of how the relationship of activity and identity was enacted through the participants' experiences.

Chapter Descriptions

Chapter 2 presents a background that supports this research, including research and practices in postsecondary education that consider the transition to postsecondary education for students with IDD as well as federal legislation that supports increased access to postsecondary education for students with IDD. Literature on identity formation and the relationship of activity and identity are covered as well. In Chapter 3 I introduce myself as author and explain the role of my personal experiences in practice and research. Chapter 4 details a pilot study that I conducted as preparation for the current dissertation research: its subject was Kendra, a woman with developmental disabilities who was

participating in a graduate-level traineeship. Chapter 5 presents the methodology of the current research, my rationale for its ethnographic methodology and procedures, and introductions of the MS program and its participants. The MS program is described in deeper detail in Chapter 6, as I frame the program and the realm of postsecondary education of students with IDD within Holland et al.'s (1998) concept of figured worlds. I present stories from my data in chapters 7 and 8, both of which allow an intimate look into the participants' experiences in postsecondary education along with my analytical and theoretical interpretations of the data. Chapter 9 concludes the dissertation with final thoughts and a discussion of remaining questions.

Chapter 2

Background

Introduction

Socio-cultural understandings of how people with intellectual and developmental disabilities (IDD) function in society have evolved throughout human history. Accordingly, cultural practices have advanced to reflect these developing understandings. In the United States, people who once would have been confined to institutions and or constrained in sheltered workshops are experiencing community living; some participate in postsecondary education (Grigal, Hart, & Lewis, 2012). For students with IDD, postsecondary education now includes certificate or degree programs at two- and four-year colleges that offer career preparation and training in independent-living and self-advocacy skills. Additionally, dual-enrollment programs allow college-aged high school students with IDD to experience education with their same-age peers.

Diagnostic terminology has evolved as well. What was formerly termed “mental retardation (MR)” is now referred to as “intellectual disabilities (ID).” Additionally, people with developmental disabilities (DD) have been accorded a separate diagnostic category as the medical and disability societies recognize that not all people with DD (e.g., autism) automatically have comorbid ID.¹ The term “IDD” is used in this dissertation to encompass a heterogeneous group of people who have DD and ID.

This chapter introduces the literature about postsecondary education for students with IDD and practices concerning them. It begins with an overview of postsecondary

education, including why postsecondary education is desirable. Information about the benefits of college for young adults without IDD is included because college offers similar potential advantages for students with IDD. Although the field of postsecondary education for students with IDD is still nascent, outcomes research is already documenting gains that are similar to those made by college graduates without IDD (Migliore, Butterworth, & Hart, 2009). Federal legislation since 1990 that supports the transition and access to postsecondary education for students with IDD is also presented. Next, the transition to postsecondary education is described as it occurs for high school students with IDD and national statistics are presented to show how many students with IDD are making the transition to college. Literature on specific postsecondary education practices and experiences for students with IDD is included as well. The chapter then turns to a discussion of identity related to the college experience; last, the discourse about identity is developed into a discussion on the relationship of activity, or occupation, and identity in occupational science.

Postsecondary Education

Reasons for postsecondary education. Universally, postsecondary education has been shown to be advantageous for employment, community participation, independence, individual choice, and quality-of-life outcomes for people without IDD (Causton-Theoharis, Ashby, & DeClouette, 2009; Hart, Grigal, & Weir, 2010; Lindstrom, Doren, & Miesch, 2011; Papay & Bambara, 2011; Stodden & Mruzek, 2010; Stodden & Whelley, 2004; Thoma et al., 2012; Thoma et al., 2011; see also Zafft, Hart, & Zimbrich, 2004). With regard to financial gain, students with a college degree can nearly double their average lifetime earnings (Gilmore, Bose, & Hart, 2001; Marcotte, Bailey,

Borkoski, & Kienzel, 2005). Postsecondary education is also critical for a majority of jobs in the United States workforce. Carnevale and Fry (as cited in Newman, Wagner, Knokey, Marder, Nagle, et al., 2011) reported that 56% of workers needed at least some college education for their jobs in the year 2000, an increase of 36% from 1959. In terms of personal and social growth, postsecondary education can serve as the transition to adulthood for students who have recently completed high school. Kuh (1995) found that college is a time to develop skills of self-direction, social interaction, and community participation. The literature shows that college is not only about mastering academic content but also about fostering personal development.

President Barack Obama emphasized the importance of postsecondary education and encouraged all Americans to further their schooling in his 2009 State of the Union address:

In a global economy where the most valuable skill you can sell is your knowledge, a good education is no longer just a pathway to opportunity —it is a prerequisite. Right now, three-quarters of the fastest-growing occupations require more than a high school diploma. And yet, just over half of our citizens have that level of education... We have one of the highest high school dropout rates of any industrialized nation. And half of the students who begin college never finish.... But it is the responsibility of every citizen to participate [in college]. And so tonight, I ask every American to commit to at least one year or more of higher education or career

training. This can be community college or a four-year school; vocational training or an apprenticeship. But whatever the training may be, every American will need to get more than a high school diploma. And dropping out of high school is no longer an option. It's not just quitting on yourself, it's quitting on your country—and this country needs and values the talents of every American. That is why we will provide the support necessary for you to complete college and meet a new goal: by 2020, America will once again have the highest proportion of college graduates in the world. (as quoted and cited in Thoma et al., 2012)

Although students with IDD do not typically exit high school with a standard diploma,² President Obama's encouragement about postsecondary education should be applied to them. Students with IDD who have participated in postsecondary education have been found to be more likely to have a paid job as well as higher earnings (Migliore et al., 2009; Zafft et al., 2004). Moreover, these students tend to require fewer work-related supports (i.e., job coaching) than their peers with IDD who did not participate in postsecondary education (Zafft et al., 2004). Finally, in terms of social participation, postsecondary education allows students with IDD to continue learning in age-appropriate environments (Neubert, Moon, Grigal, & Redd, 2001; Thoma et al., 2011). Since this State of the Union address, President Obama has signed federal legislation that makes college, and thus economic prosperity, more accessible to American students with IDD.

The Higher Education Opportunities Act of 2008 (HEOA) created model demonstration programs to support the development of transition and postsecondary education programs across the nation while expanding financial aid benefits to students with IDD (Eidelman, 2011; Grigal et al., 2012; Grigal, Hart, & Migliore, 2011; Smith Lee, 2009; Stodden & Mruzek, 2010; VanBergeijk & Cavanagh, 2012). The act formally recognizes postsecondary education as specialized programs at institutions of higher education as well as dual-enrollment programs in which college-age students with IDD attend their high school and a higher education institution simultaneously (Thoma et al., 2012). Eligible students

A) have cognitive impairment characterized by significant limitations in

(i) intellectual and cognitive functioning, and

(ii) adaptive behavior as expressed in conceptual, social, and practical adaptive skills; and

B) are currently, or were formerly, eligible for a free appropriate public education under the Individuals with Disabilities Education Act. (HEOA, 2008)

Making the transition happen. The Individuals with Disabilities Education Act of 1990 (IDEA; reauthorized 2004) mandated that both public and private schools develop plans for students with IDD to transition to post-school activities (Noyes & Sax, 2004). This directive supports individualized transition plans for students with IDD from high school to postsecondary activities such as continued education, employment, adult services, community participation, and independent living (Chiang, Cheung, Hickson, Xiang, & Tsai, 2012; Eidelman, 2011; Hendricks & Wehman, 2009; IDEA, 2004; Johnson & Nord, 2010/11; Roberts, 2010; Shogren & Plotner, 2012; Stodden & Mruzek,

2010). These transition services must begin when each student is 14 years of age.

Participants in the transition planning process include the student along with his or her parents/guardians and teachers from special education and general education (when applicable). Student or parent advocates, therapists, and representatives from vocational rehabilitation or postsecondary education programs may also participate. During this process, students who wish to transition to postsecondary education indicate their continued education goal(s) in an individualized plan. School supports are then positioned to help the student achieve his or her stated goal(s).

Unfortunately, this procedure—while mandated by law—is not fully implemented in American schools. Grigal et al. (2011) found that students with IDD are less likely than other students with disabilities to have postsecondary education as a transition goal. Further, the goals of students with IDD cater more toward sheltered and supported employment than the goals of students with other kinds of disabilities. The exclusion of postsecondary education as a transition goal may be due to limited knowledge about postsecondary options, barriers to accessing postsecondary education (e.g., proximity and finances) or lack of support from family and educators.

National postsecondary figures for students with IDD. Enrollment numbers of students with IDD are low despite the increased access to and benefits of postsecondary education. According to the National Longitudinal Transition Study-2 (NLTS2), fewer than half of students with IDD receive postsecondary education (Chiang et al., 2012; Newman et al., 2011).^{3, 4} However, participation of students with IDD in postsecondary education settings increased in the United States from 1990 (8.4%) to 2005 (28.1%) (Newman, Wagner, Cameto, Knokey, & Shaver, 2010). The NLTS2 data also show a

slow but steady increase (to 28.7%) in participation of students with IDD in postsecondary education between 2005 and 2009 (Newman, Wagner, Cameto, & Knokey, 2009; Newman et al., 2011; Sanford, et al., 2011). With the 2008 reauthorization of the HEOA, this rise is likely to continue.

Think College is an initiative at the University of Massachusetts Boston's Institute for Community Inclusion that aims to support the research and practice of postsecondary education for students with IDD. As of March 2013, the Think College online database of postsecondary programs for students with IDD numbered 204 in the United States (Think College, 2013), including two- and four-year colleges and universities, and trade schools. Students served by these programs may be in high school, attending dual-enrollment programs for students ages 18 to 21, or adults who have completed high school. According to a 2008 survey of 52 postsecondary programs for students with IDD, the median enrollment for these programs was 12 (Papay & Bambara, 2011). Reasons for offering a postsecondary program on a college campus included gaining employment opportunities or training, experiencing inclusion with same-age peers, developing independent living skills, and participating in college classes. The surveyors found that the majority of classes taken for credit were vocational and remedial classes; academic, health and fitness, and arts classes were typically audited. This finding implies great disparity in the inclusiveness of the postsecondary experience for students with IDD. In 2009, a survey of 158 postsecondary programs from 39 states affirmed this disparity by finding that nearly half of the responding programs offered mostly segregated academic experiences for students with IDD (Grigal, Hart, & Weir, 2012). This study confirmed that the experiences of students with IDD in postsecondary

education are quite variable from one program to another in terms of practices (e.g., residential opportunities, student support, inclusive or segregated education, etc.) and foci (e.g., employment vs. inclusive academics).

State of the Literature of Postsecondary Education for Students with IDD

Neubert et al. (2001) conducted a review of articles in professional journals about postsecondary education from the 1970s to the end of the 20th century. Although they only found one empirical study, the authors were able to compile a thorough list of postsecondary programs for students with IDD across the United States and Canada. The authors suggested that, despite segregated learning, students with IDD began to attend classes on college campuses in the 1970s because of social movements supporting reintegration that arose in the era of deinstitutionalization; in addition, specialized programs were developed to train people with IDD for employment. Since their inception, postsecondary programs for students with IDD have been housed both at community and state colleges. Thoma et al.'s (2011) synthesis of literature built upon Neubert et al.'s review, with the addition of a critical appraisal of literature published from 2001 to 2010 about postsecondary education for students with ID. The authors explored changes in postsecondary programs since Neubert et al.'s review as well as outcomes and benefits of postsecondary education.

Programmatic practices. As found in the syntheses mentioned in the previous section, literature about postsecondary education for students with IDD has often been limited to the discussion of systematic practices of existing postsecondary programs. In their survey of administrative stakeholders in two specialized programs, Causton-Theoharis et al. (2009) explored the benefits of and obstacles to program practices and

identified key benefits for students with disabilities, students without disabilities, and faculty. Benefits included access to educational opportunities for students with significant disabilities who were otherwise ineligible for postsecondary education, increased social inclusion, and new methods of instruction to teach people of varying abilities.

Impediments at the institutional level included faculty resistance, barriers to accessibility, and difficulty accessing the library and identification cards that are necessary for student participation in the college environment.

Hart et al. (2010) conducted an extensive review of practices in postsecondary programs across the nation for students with IDD. They found certain practices to be commonplace (e.g., instruction in natural environments, person-centered planning, multidisciplinary coordinating teams, educational coaching, employment experience, and a focus on developing students' self-determination), and determined that these reflect the values of successful participation, inclusion, and quality of life that are inherent in the culture of postsecondary education for students with IDD. In this study, which offered an innovative perspective on curricular practices in postsecondary education, Hart et al. advocated for success to be demonstrated by personal growth rather than defined by academic achievement: "...a successful college experience is measured [by] increased learning, increased independence and self-determination, and positive social experiences, among others" (p. 137).

Nonetheless, Hart et al. argued for the preservation of academic rigor for students with IDD, for example by placing responsibility on students and their supports as a way of ensuring successful participation in college courses and achievement of self-determination. Strive University, a specialized postsecondary program for students with

IDD at the University of Southern Maine, upholds this stance. A stipulation of the program's university sponsorship has long been that university instructors of inclusive classes will not modify their courses to accommodate Strive students (P. Brown, personal communication, December 28, 2012; Schmidt, 2005).⁵

While program staff and faculty can offer firsthand perspectives about postsecondary education, insight from the students who are experiencing the programs is necessary to understand the full effects of postsecondary practices. Autobiographical literature in the field of postsecondary education for students with IDD emphasizes individualized supports for students' postsecondary experiences, known as person-centered planning (Grigal, Neubert, & Moon, 2002). Based on their own experiences, Prince-Hughes (2003) and Robertson and Ne'eman (2008), three scholars with autism, contended that postsecondary programs must be capable of meeting students' executive functioning, sensory processing, and mental health needs. Prince-Hughes also acknowledged that behaviors that are frequently considered disruptive (e.g., rocking) should be understood as mechanisms that help students with autism focus in class. In addition to these autobiographical works and the perspectives from people with IDD that they offer, further insight into postsecondary education for students with IDD can be obtained through exploration of the engagement of college students with DD and IDD in college experiences.

Research about Students with IDD Experiencing Engagement in Postsecondary Education. Dolyniuk, Kamens, Corman, DiNardo, Totaro, and Rockoff (2002) conducted a pilot study of a social-modeling and skills-training program for older high school students with DD. The program was a brief (three-week) intervention in

which the students, aged 16 to 20 years, spent a total of nine hours in job-sampling roles at a local, private four-year university. University students enrolled in a summer-session psychology course on mental retardation mentored the high school students. The authors gathered quantitative and qualitative data from the high school participants, university student mentors, and high school and university faculty in the forms of journals, interviews, and surveys. Their findings suggested that developmentally appropriate environments can offer reciprocal benefits for people with and without disabilities.

Longer-term dual-enrollment programs have yielded similar and additional benefits. Redd (2004) conducted a program assessment at a community college of a year-long dual-enrollment postsecondary program for high school students with significant disabilities. Although the assessment's primary focus was on programmatic practices, Redd sought input from the participating students, their parents, and alumni about the participating students' engagement in postsecondary experiences during the program. All of these groups expressed mixed feelings about the overall educational experience. For example, people in each group conveyed desire for a more-challenging academic curriculum. Still, students and alumni reported that the program had taught them important skills, was less restrictive than high school, and had allowed them to make friends with college students. Inclusive encounters were among the most highly regarded aspects of the program.

Casale-Giannola and Kamens (2006) found similar benefits to dual enrollment for Jacqueline (pseudonym), a high school student with Down Syndrome who took a public speaking course at a local university and expressed satisfaction with her inclusive interactions with the college students in her class. She developed a friendship with her

educational coach, who was also a student at the university. In addition to the social experiences and academic content, this dual-enrollment experience expanded Jacqueline's transition options post-high school: she returned to her high school curriculum upon completing her public speaking class, but has expressed interest in going back to college. Whether or not she did pursue further higher education, Jacqueline's experience with postsecondary education gave her a way to relate to her same-age peers when they talk about college.

Hamill (2003) studied a young woman with Down Syndrome, Megan (pseudonym), who had completed high school and was attending two college courses at a four-year private liberal arts college. The author observed and interviewed Megan, as well as other students and faculty who participated in her experience. As with the dual-enrollment experiences described by Redd (2004) and Casale-Giannola and Kamens (2006), Hamill determined that attending college yielded social and scholastic opportunities for Megan, who enjoyed interacting with same-age peers while learning how to master educational content. Her experience of the postsecondary curriculum as a college student varied from those of the dually enrolled participants in the aforementioned studies, however. As a participant in a specialized non-degree track, Megan lamented not receiving grades for her curricular efforts. She also felt that feedback was a vital aspect of the college experience.

Identity

Identity development through the college experience. Changing environments has been described as influencing identity development because the process necessitates new routines (Huot & Laliberte Rudman, 2010). Therefore, transitioning to college can

be seen as a period of identity transition for young adults. It is a time to develop student and peer identities while kindling the development of future worker and community participant identities. Holland and Eisenhart (1990) demonstrated these identity transitions in their ethnography of college women (without disabilities) in the American South in which they explored how students' identities developed through engagement in college activities (i.e., schoolwork and socialization). Those who hailed college as an opportunity to learn from experts and develop experience presented salient student identities, whereas those who found schoolwork to be arbitrary and favored socialization over schoolwork portrayed more salient identities within peer friendships and romantic relationships. These identities during college were also found to correlate with identities of worker or spouse after college.

Anctil, Ishikawa, and Scott (2008) researched identity development of college students with learning disabilities, specifically the emergence of academic identity, and produced a model based on their findings that depicted identity as developed through persistence, competence, career decision making, and self-realization. The three formative factors of persistence, competence, and career decision making were reflected in students' access to university resources that accommodated their educational needs. Like Holland and Eisenhart's work (1990), Anctil et al.'s study supports the relationship of occupation and identity for students with learning disabilities. Unfortunately, there remains a paucity of further research that considers identity development of college students with IDD.

Identity of individuals with IDD. The study of identity of individuals with IDD is decidedly minimal in the occupational science and occupational therapy literature. My

search produced one study, by occupational scientist Nancy Bagatell (2007), that was published in a journal of disability studies. Bagatell's writing details the experiences of a young adult with Asperger's syndrome who faced identity struggles as he navigated the "Aspie" and the "Neurotypical" figured worlds (see Holland et al., 1998 and Chapter 6 of this dissertation for further description of figured worlds). This young man, Ben, found that "acting normal" was difficult in the neurotypical world of people without autism; instead, his preferred practices of socialization and participation were accepted in the Aspie world. Ben's ability to engage in occupations with a sense of normalcy in the Aspie world facilitated and gave meaning to his identity as a person with autism. Although Ben did not have an intellectual disability, his developmental disability makes his story relevant to this review because this dissertation considers people with intellectual disabilities and developmental disabilities as a heterogeneous group. The fact that only one study of this type was found in the literature related to occupational science elucidates the lack of research on identity of individuals with IDD.

Identity and Occupation

The relationship of identity and occupation in occupational science. Charles Christiansen and Debbie Laliberte Rudman pioneered the study of identity and occupation, thereby paving the way for occupational therapists and scientists to explore the association between identity and occupation as it relates to practice and theory. In his 1999 Eleanor Clarke Slagle Lecture, Christiansen conceptualized occupation as the medium for identity development and expression and offered four propositions of identity centered on this stance: (a) Identity is an overarching concept that shapes and is shaped by our relationships with others; (b) Identities are closely tied to what we do and our

interpretations of those actions in the context of our relationships with others; (c) Identities provide an important central figure in a self-narrative or life story that provides coherence and meaning for everyday events and life itself; and (d) Because life meaning is derived in the context of identity, it is an essential element in promoting well being and life satisfaction.

Similarly, Laliberte Rudman's (2002) research with seniors, mental healthcare consumers, and caregivers of stroke survivors affirmed that people express who they are through occupation. The seniors and caregivers in her studies qualified their occupational participation as a way of expressing their individuality, while the mental healthcare consumers reported engaging in occupations to portray a valued identity (e.g., student or worker). Laliberte Rudman also argued in support of a dialectical relationship of identity and occupation based on her findings, asserting that "Theory and research regarding the links between occupation and identity need to address both how identity is shaped by occupation and how occupation is shaped by identity" (p.17).

Both Christiansen's (1999) and LaliberteRudman's (2002) formative stances, which emphasize the social nature of identity, align well with the already-established social nature of occupation. They depict people engaging in socially accepted occupations in order to project identities that would be socially accepted by others. These seminal works provide critical insight into the dynamic chemistry of identity and occupation for researchers of occupation and clinicians in the field. In his chapter on occupation and identity, Christiansen (2004) referenced a quote from American psychologist Abraham Maslow that exemplifies the association among these two constructs: "We do what we are and we are what we do" (p. 134). In fact, Maslow's

quotation appears frequently in Western conversations. When meeting new people, the query “What do you do?” is customary. People generally ask this question to gain insight about the individual through the activities in which he or she engages; typically, they are referring to vocational activities (Unruh, 2004). Noting the strong American value of the worker identity, Dickie (2003) explored the development of the worker identity of American crafters and found that crafters followed certain rules for home and social contexts that supported their worker identities. Engaging in occupations that met these rules, such as maintaining a workplace in the home and presenting their work at craft fairs, facilitated their establishment of a worker identity.

Occupational identity. Occupational identity has been an evolving construct in occupational science and occupational therapy.⁶ Kielhofner (2002) defined occupational identity as “a composite sense of who one is and wishes to become as an occupational being generated from one’s history of occupational participation” (p. 120.) His definition was essentially based on the assumption that people’s identities were constructed with intention to impact their futures. Later that year, Unruh, Versnel, and Kerr further conceived occupational identity as

...like a fabric of occupational choices that conveys something
about who a person is at particular points in her or his life.

Occupational identity does not convey the whole of an individual
but it is a core concept of the person as an occupational being...
conceptualized as the expression of the physical, affective,
cognitive and spiritual aspects of human nature, in an interaction
with the institutional, social, cultural and political dimensions of

the environment, across the time and space of a person's life span,
through the occupations of self-care, productivity and leisure. (p.
12)

Unruh (2004) supported her theoretical construction of occupational identity with an observational study of John, a former research participant. She found that John's occupational identity "evolved over time and was shaped in different ways by his life experiences, his choices and his environment" (p. 292). Unruh concluded that occupations of productivity, leisure, and self-care were paramount to the construction of occupational identity.⁷

The construct of occupational identity began as individualistic and Westernized (Laliberte Rudman & Dennhardt, 2008; Phelan & Kinsella, 2009). In their review of occupational identity literature, Phelan and Kinsella identified four theoretical assumptions underlying the construct of occupational identity: (a) The individual controls identity formation; (b) Individuals choose occupations that guide the development of their occupational identity; (c) Productivity is a salient aspect of occupational identity; and (d) Occupational identity is developed based on society's approval and acceptance. Laliberte Rudman and Dennhardt and Phelan and Kinsella contested this perspective by arguing for the socio-cultural development of occupational identity.

Dickie, Cutchin, and Humphry (2006) disputed the individualism frequently attributed to occupation by contending that "occupation rarely, if ever, is individual in nature" (p. 83). According to these authors, an individualistic perspective of occupation is problematic because it parses the individual and occupation as separate entities that can be separately deconstructed. These authors do not discount the individual in the

occupational experience, but rather emphasize that the individual and the occupation transact as situational processes on the same level instead of limiting the definition of occupation to a thing or an action that an individual performs. Dickie et al.'s transactional perspective can be used as a counterargument to Kielfhofner's (2002), Unruh's (2004), and Unruh et al.'s (2002) individualistic conceptualizations of occupational identity.

This dissertation considers identity to be inherently imbued with social and contextual factors that go beyond the individual. Aligning with Dickie et al.'s (2006) transactional perspective, identity will be considered a transacting factor in the participants' experiences. Occupational identity will not be incorporated into this study because of its individualistic connotation.

Conclusion

In this chapter I have introduced the topic of postsecondary education for students with IDD through a review of the transition to postsecondary education, federal legislation that supports the transition to postsecondary education, and current literature in the field, including studies of programmatic practices and how students with IDD experience engagement in postsecondary education. As noted, the growth of opportunities for people with IDD to experience postsecondary education like their peers without IDD means that it is important to explore how such students engage with the programmatic practices described in the previous sections. Research in this area has been largely limited to dual-enrollment or part-time university enrollment and has been dependent upon surveys and program evaluations produced by administrative stakeholders. This study takes a closer and more holistic look at how students with IDD

experience engagement in postsecondary education at a four-year university-affiliated program for students who have completed high school.

I have also explored the dialectical relationship of occupation and identity in this chapter. When I chose to focus on a transition period (i.e., postsecondary education), I anticipated that I would find rich opportunities to observe the intersection of undertaking college student activities and simply being a college student. In Chapter 4, where I will present the pilot study I conducted in preparation for this doctoral research, this relationship between occupation and identity in postsecondary education will be further supported.

Information gleaned from my study may inform programmatic practices and values, as well as structures of engagement in postsecondary education for students with IDD on cultural, institutional, and social levels. This applicability is based on the current study's focus on the transactional process of engagement in postsecondary education, rather than on the outcomes of postsecondary education that presently dominate the literature. Information from this study can also contribute to the discourse on identity and occupation in occupational science, as well as support a holistic, occupation-based approach to the study of engagement in postsecondary education in the fields of higher education for people with and without disabilities.

Chapter 3

Positionality

My previous clinical background, research history, and academic and professional activities all helped shape the personal values that are inherent in this research. My experiences while conducting this study also contributed to the development of these values. This chapter describes the values that I came to recognize and appreciate as my positionality.

Personal Background

Clinical training and experience. Prior to returning to graduate school, I earned my master's degree in occupational therapy and worked for two years at a trauma hospital as an occupational therapist. My specialized training prepared me to work with populations of varying capacities in home, medical, community, and educational environments. I framed my clinical practice with a holistic perspective, which meant that I strove to appreciate the individual who was receiving services as a part of a larger system. As a result, I developed questions about occupation being greater than the individuals whom I was "treating": How did my clients' temporary stays in an inpatient rehabilitation facility impact their experiences of occupation and identity? How might their occupations and identities be different when they returned home? This approach to practice was not congruent with the microcosmic medical system that focused solely on rehabilitating individual consumers with objectified ailments. After researching occupational science and determining that my questions about occupation could best be

answered in this discipline, I left clinical practice to pursue doctoral studies in occupational science.

Research history. During my master's program, I conducted quantitative time-use research on the activity patterns of adults with developmental disabilities (Furgang, 2006). The adults in my study lived in group homes and participated in day habilitation programs. My research aims included analyzing the participants' time spent in categories established by the research team (e.g., self-care, active recreation, passive recreation) in order to describe the general activity patterns of this population. My focus on activity is transferable to and expanded in the current study, in which I examine activity as only one dynamic aspect of a larger situation. In the current research I consider how activity transacts with other situational elements (e.g., the environment, the university culture, identity, and peers) to understand the experiences of this cohort of college students and also explore the relationship of identity and activity.

Current academic activities. I am a doctoral candidate in occupational science who has developed an enhanced appreciation for the holistic nature of occupation and a research interest in the occupational experiences of college students with intellectual and developmental and developmental disabilities. I have received generous funding for a majority of my doctoral education through a Leadership Education in Neurodevelopmental Disabilities (LEND) fellowship at the Carolina Institute for Developmental Disabilities (CIDD). My work at the CIDD revolved around education, research, and policy in the area of IDD. As part of my doctoral studies I co-designed and co-instructed a course about IDD across the lifespan using a problem-based curriculum. Students in the course learned about IDD through clinical cases written by practitioners.

This course, which was more than a series of lessons about diagnostics and symptomatology, taught students to appreciate the entire experience of disability from a socio-cultural perspective. This course was required for all LEND students but was also open to the rest of the university's graduate community.

Professional memberships. My work in education and research in the area of IDD as a LEND fellow has allowed me the opportunity to participate in the North Carolina Postsecondary Education Alliance (NCPSEA). Led by two CIDD faculty members, the NCPSEA has blossomed into a large group of leaders in IDD across North Carolina with the mission to “expand the options for postsecondary education for individuals with developmental disabilities throughout North Carolina” (<http://cidd.unc.edu/services/default.aspx?id=60>). Through my work with the NCPSEA, I have made contacts with people from postsecondary education programs statewide, including community colleges and universities. I have received supportive feedback from alliance members about my research.

Developing a Focus: An Iterative Process

My initial goal for this project was to explore a seemingly uncharted area of postsecondary education for students with IDD: the student experience. My professional conversations, personal experiences, and reviews of current literature showed that research in this area was largely focused on programmatic practices and outcomes, for example: how college improves vocational opportunities, how experience in a college program for students with IDD might result in decreased needs for professional services (e.g., therapies), and what types of supports are available for college students with IDD when they participate in specialized programs. As an occupational therapist and scientist,

I felt that the occupational experience of college students with IDD was underappreciated in the literature.

I set out to explore experiences of engagement in occupations of college students with IDD because I felt these occupational experiences would provide insight into the development and implementation of postsecondary programs. As I continued through this project, intent on studying students' experiences in the program, I noticed that the future was a salient aspect of both the curriculum and the students' goals. Because goals are inherently future-focused, I quickly realized that the future could not be overlooked. In other words, a holistic approach to studying occupation must take into account how current experiences will influence future experiences. Accordingly, my data showed me that studying college experiences allowed for consideration of future occupations. The students were learning how to participate in the university and its surroundings: how to navigate the campus, how to complete assignments, how to partake in college activities, how to intern at local businesses. These were the skills they would take with them after graduation and implement as residents, workers, and community members.

The theoretical and practical link between present occupational participation and future experiences was explicated by Malcolm Cutchin in the 2012 Ruth Zemke Lecture in Occupational Science. Reflecting on pragmatist John Dewey's conceptualizations of occupation, Cutchin proposed:

Occupation as inquiry means that enabling occupation is to
cultivate better lives and societies through enhanced social action.

Occupation is extensive through time and situations because

knowing how we do things here and now via occupations affects
future life and occupations in other situations. (p. 10)

The students' occupational pursuits that I studied were essentially preparing them for their futures. Thus my initial understatement of the significance of the future developed into an introspective interpretation of it.

A blending of disciplines. Occupational science was a fitting academic discipline to house this research due to my focus on function and engagement, but this study also aligns with the social and political aims of disability studies (Baglieri, Valle, Connor, & Gallagher, 2011). According to Watson (2012), the field of disability studies perceives disability as a factor of social and environmental barriers. This consideration for the multifaceted influences on daily life for people with disabilities coincides with the perspectives of occupational science. This study was a seemingly amalgamation of occupational science and disability studies because I investigated the relationship of sociocultural factors and the personalized experiences of the students' engagement.

Further, this study aligns with a field related to disability studies known as disability studies in education (DSE). DSE addresses disability and students' participation in special education, specifically attending to the meaning that educators place on students' differing abilities (Baglieri et al., 2011). The present study expands the initiatives of DSE to the postsecondary setting. It supports DSE's call to increase support for various learning needs at all levels of education. The marginalization of people with disabilities, specifically in postsecondary education, was the impetus for this research. My focus for this project was on the daily function of college students with IDD in relation to their multifaceted transactions with the sociocultural environment. Along with

fellow occupational scientists and disability rights researchers, I stand in opposition to a medicalized interpretation of disability as an issue within the person (Baglieri et al., 2011; Longmore, 2000; Scotch, 2000; Watson), instead understanding disability as socially constructed. In adherence to my position, I found it unnecessary to disclose individual participants' diagnoses. This stance allows the reader to understand the participants through their occupations rather than disability-focused labels.⁸

Researcher as Participant

I was initially skeptical about postsecondary education for students with IDD. Out of concern that college would essentially be equivalent to the students' experiences in high school special education, I wondered how similar their experiences could be to those of their peers without disabilities. What I found transformed my perspective. As I immersed myself in data collection I became a proponent of my host program and became aligned with their model of self-determination and community participation, to the point of defending the program against critics who questioned its commitment to the students' vocational success. In short, some might say I "went native".

W. Paul Vogt (2005) defined "going native" as an anthropological term that describes researchers who lose their objectivity and become part of the culture they study. Vogt explained that this identity shift is especially common in studies that include participant observation; the precise level of cultural immersion at which one becomes native, however, is controversial in the academy. For example, scientific philosopher Thomas Kuhn (1970) described going native as "thinking and working in, not simply translating out of, a language that was previously foreign" (p. 204, as cited in Tresch, 2001). Anthropologist John Tresch argued that going native is more than translation: it

necessitates conversion, as when “the researcher comes to experience the world in the same terms as the people he or she studies” (p. 303).

By Vogt’s and Kuhn’s definitions, I probably did go native during this research. I attended classes and social activities with the students, adopted terms from their cultural lexicon (e.g.: self-determination, advocacy), and felt a sense of pride through my affiliation with the program. Still, I did not complete the homework assignments or set personal goals, and I have never been diagnosed with an intellectual or developmental disability. For these reasons, despite my congenial relationships with the participants, when I collected data I still thought of myself as an outsider coming into their world. This self-image, which remained constant, means that I might not have reached the idyllic state that Tresch praised so highly. In either case (i.e., whether I truly went native or maintained a barrier of objectivity), it is still important to reflect on how I might have functioned both as a researcher and a participant.

Although I had no comprehension of how my presence would influence the data when I formulated the proposal for this project, I rapidly became a very real part of the students’ world. They accepted me as a peer; they included me in their conversations; and they invited me to their activities. Even the student life support staff (a group of college students without disabilities who assisted the students after school and on weekends) considered me to be part of student culture. When contentious issues emerged between support staff and students, I was involuntarily “sided” with the students. In general, support staff tended to detach themselves—almost with an air of condescension from the students—and, consequently, from me.

The students, who trusted me as they would their friends, confessed intimate details about their social lives although, knowing that I was not quite native to their group, they often added the caveat of confidentiality to our sensitive conversations. I appreciate that my role in their lives allowed them to discuss certain details with me. These conversations would not and could not have taken place had I not become part of their culture.

Methodological Developments

This study began as a multiple case study with 10 participants. I planned to study each of them through observing their activities and interviewing them about their experiences. My analysis was proposed to involve thematic case analyses that would describe the typical experiences of college students with IDD. As I collected data, however, this methodology proved to be too limiting; my “cases” were more integrated than separate and I found my interest was in the culture of the students and program, rather than individual actions. As a result, I soon found myself studying occupation and identity through the culture of Making Strides (MS) rather than observing, interviewing, and drawing conclusions about individual people.

The acknowledgement that occupation comprises more than the individuals who engage in it reflects the transactional perspective developed by my mentors and doctoral dissertation committee members: professors Malcolm Cutchin, Virginia Dickie, and Ruth Humphry (see Dickie, Cutchin, & Humphry, 2006). With their guidance, I realized that I could not thoroughly study occupation and identity without appreciating the situational context, which included the connections among my “cases.” Thus, my multiple case study grew into an ethnography. I continued collecting data on the primary participants,

but my level of analysis became the larger culture of the Making Strides program, with considerations of the state university and the local community. The ethnographic process deepened my research by allowing me to explore the situated nature of the students' experiences.

Chapter 4

Pilot Study: Kendra

As a doctoral fellow at the Carolina Institute for Developmental Disabilities (CIDD), I served as an educational coach for Kendra, a trainee with a developmental disability (DD).⁹ I seized the opportunity to use this experience as a pilot study for my dissertation work. Kendra was the CIDD's first trainee to have a DD, and she was the first such trainee in the CIDD's Leadership Education in Neurodevelopmental Disorders (LEND) training network that the CIDD was aware of. Her age (more than 30 years old) and disability made her a nontraditional student, but she had gone to college and earned an undergraduate degree so she had previous postsecondary experience. Kendra had been actively involved at the CIDD in self-advocacy initiatives for people with disabilities; she co-designed and co-led self-advocacy trainings. Kendra's role as a self-advocate made her a natural choice to recruit for this novel training experience. Working with CIDD faculty and staff, and Kendra, made me an integral player in piloting this graduate-level traineeship for individuals with DD during the 2010–11 academic year. Kendra's responsibilities as a trainee included service work at the CIDD, participation in a year-long leadership development program, and participation in two semesters of a graduate-level problem-based learning course about DD.

Faculty members at the CIDD nominated me to be Kendra's coach during her traineeship because of my occupational therapy work with people with DD. Additionally, I had significant experience with the required trainee course about DD across the

lifespan. Because I had co-developed the course and was co-teaching it during Kendra's year as a trainee, Kendra's faculty mentors at the CIDD felt that I could provide the appropriate support to facilitate her success in both the traineeship and the course. I gratefully accepted and seized this opportunity, with Kendra's consent, to study her experience as a pilot study for my dissertation.¹⁰ This pilot study allowed me to explore how a student with a DD experienced a postsecondary program while also practicing the skills of qualitative research.

I conducted weekly meetings with Kendra to discuss her participation in the traineeship, encouraged her to keep a reflective journal about her experiences, maintained my own research and reflective journal, and explored the adaptations necessary to support her academic involvement. I also met with Kendra and her academic advisors throughout the pilot study and collected notes from each encounter. Data collection began during the summer prior to the 2010–11 academic year and concluded in May 2011. I met with Kendra 12 times and with Kendra and/or her advisors five times; engaged in approximately 30 email conversations about Kendra's participation with her, CIDD faculty, and CIDD staff; met with my advisor in Occupational Science approximately five times for peer debriefing; and wrote 21 entries in a reflective journal. I was able to collect only four journal entries from Kendra despite my constant encouragement and her frequent assurance that she would submit more written reflections. Upon conclusion of data collection, I re-read all of the data, sorted it, and conducted thematic analysis to organize it into domains that reflected important points of Kendra's traineeship. I used this focus to generate broader themes of Kendra's experiences: identity and occupational

engagement, accommodations versus modifications, expectations, and balancing lives. These themes are discussed in the following sections.

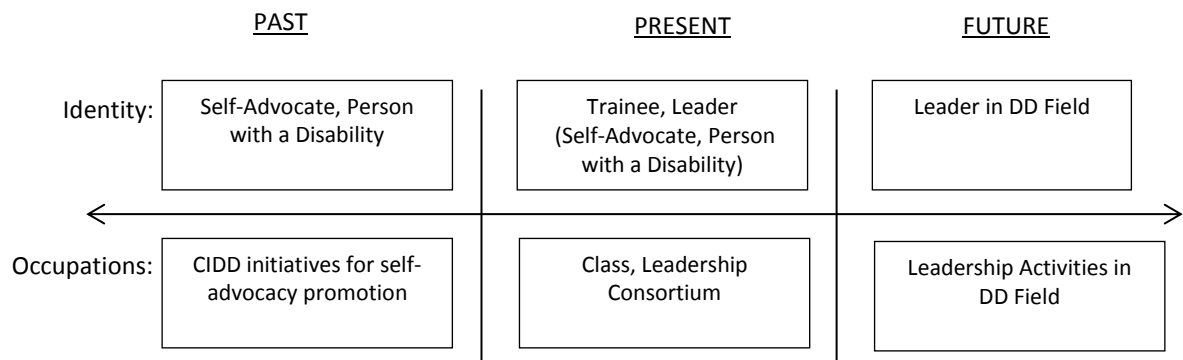
Identity and Occupational Engagement

Kendra's college experience took place approximately 10 years prior to this traineeship, so her identification as a college student was no longer apparent in her everyday routines. Her understanding of what a college student is and what a college student does reflected the historical, physical, and social contexts of her past undergraduate experience. More prominent now was Kendra's identification as a self-advocate with a disability.

Kendra's traineeship at the CIDD challenged her to balance her established identities of self-advocate and person with a disability with redevelopment of a student identity (hereafter, trainee identity) that was constructed by her mentors and the program's practices. Unlike her previous experience in college, Kendra now had to come to an off-campus building (which required pre-arranged transportation), take her own notes using an electronic tablet, work with other members of a multidisciplinary graduate student team, engage in graduate-level academic material, complete graduate-level assignments and group projects, and utilize resources (e.g., the library and the Internet) in new ways. Her socialization with classmates was limited to online communications (required for class) and in-class group work related to course content. At the same time, she was also expected to develop the identity of "leader" in the field of developmental disabilities (CIDD, 2013a) because her traineeship was part of the LEND program. All LEND and CIDD trainees were required to attend a year-long leadership training consortium that was meant to foster their identities as leaders in DD fields. Although

Kendra had practical leadership skills that she had acquired through her self-advocacy work, this consortium implemented a content-specific leadership curriculum. Figure 1 illustrates how I envisioned Kendra’s identities and occupations at the start of her CIDD/LEND traineeship. This conceptual map is based on the construction of Kendra’s trainee experience by program practices and expectations.

Figure 1. Conceptual Map of Kendra’s Anticipated Experience in the Traineeship



This conceptual model parses Kendra’s identities and occupations into the temporal organization of past, present and future. It shows her past identities and their associated occupations as separate from those that the present traineeship was constructing. Kendra’s past identities remain apparent but appear in parentheses to reflect their secondary level of importance. The future identity and associated occupations reflect the goals of Kendra’s traineeship.

Kendra initially struggled with balancing her identities of self-advocate, person with a disability, trainee, and rising leader. At the first trainee event, the Maternal and Child Health Leadership Consortium’s three-day intensive workshop, Kendra enacted the identities of self-advocate and person with a disability.¹¹ She asked questions that were related to people with disabilities and accessibility. However, this activity seemed to

impede her ability to participate in the consortium, which including listening to and discussing the leadership content. The following example from my journal illustrates Kendra's struggle:

At the end of Day 2, I encouraged Kendra to put the advocacy hat aside to focus on her role as a participant in this workshop—a leader in progress. She heard me say that she should not be an advocate... and she broke down... I told her this would be a difficult process, learning how to balance her different roles, but she [shut down] and appeared hesitant to continue with the process. (September 3, 2010)

I realized that Kendra's self-advocate and disability identities were driving her occupational engagement in the consortium so much so that they were hindering her ability to develop the trainee and leader identities.

From an occupation-based approach, I felt I could best support Kendra to be successful in her traineeship by facilitating her engagement in occupations related to the trainee and leader identities. Kendra and I worked together to develop personal long- and short-term goals as well as activities that would help her attain those goals. These activities guided Kendra to enact her new identities of trainee and leader while balancing these identities with her established identities of self-advocate and person with a disability. For example, Kendra's goal to balance her history of advocacy work with her work at the CIDD was to be accomplished by completing two separate journals: a personal one that would reflect her passion for advocacy, and another for her trainee and academic experiences. It was my hope that engaging in this journal-writing occupation

would contribute to the development of the trainee and leader identities without the firmly established advocate and disability identities complicating the process. In turn, I hoped that Kendra's growing identification as a trainee and leader would contribute to her further engagement in trainee and leader occupations.

I was naïve to expect such a bold parsing of identities and occupations, as I witnessed firsthand over the course of this experience that multiple identities and accompanying occupations remained dialectically interwoven throughout time. That fall semester, as a personal undertaking, Kendra wrote an article about being a trainee and submitted it to a non-peer-reviewed interest magazine. She described this intertwining of identities and occupations by stating: "I'm trying to resolve the issue of seeing myself as an advocate. I've already made that part of my life clear to everyone. In this setting everyone in the course and faculty are advocates for people with disabilities." This statement reflects the melding of identities across occupations. It shows that Kendra's identity as an advocate could be enacted through her personal occupations while also participating in trainee occupations (e.g., the graduate-level course). Kendra's statement also shows that occupation (e.g., advocacy) may be enacted across various identities. She could advocate through the identity of self-advocacy trainer and through the identities of trainee and leader. My realization of the dialectical relationship of occupation and identity, coupled with Kendra's reflection, rendered the conceptual map in Figure 1 inadequate to appreciate her experiences.

Developing the new trainee and leader identities was challenging for Kendra. Although she was very capable of advocating for people with DD, she struggled with the demanding academic occupations required of all trainees (e.g., professional writing and

research involving scholarly resources). Kendra felt the need to “keep up” with her peers but also felt academically and emotionally inferior to them. In an October 2010 entry from her traineeship journal she wrote, “What Am I doing here? Why I a trainee? Is my voice important? Do I add anything to this. Group?”¹²

As she faced the often-all-encompassing feeling of inferiority during engagement in project and coursework, Kendra gained more confidence and pride and developed new identities. By November, Kendra had become skilled at posting online for the academic course. I complimented her on her posting through an email communication, to which she responded, “I posted the info on my own on Saturday afternoon! Yay!” This was the point at which Kendra began assertively referring to herself as both trainee and leader. She began to take on new and challenging occupations, such as stepping up to be the group facilitator when a peer did not come to class. Doing so further confirmed her trainee identity. In her final traineeship journal entry, Kendra’s writing reflected her identification as a trainee, equal membership in the trainee cohort, and engagement in trainee occupations: “I hope to continue my friendships with some trainees.... Both the [academic] course and the Leadership workshops were very hard on me personally sometimes, but I kept going and completed everything just like all the other [CIDD] trainees” (May 11, 2011).

As the end of the school year approached, Kendra spoke of the confidence and pride she was gaining from the traineeship and referred to specific activities that included project work with CIDD faculty, schoolwork for the required course, and participation in the accompanying leadership consortium for trainees. Through engagement in these activities, Kendra developed the identities of trainee and leader in the field of DD.

Moreover, as Kendra self-identified as a trainee, she found new occupational possibilities. Kendra's development reflected significant personal and professional growth. Her experience evidenced the dynamic, dialectical relationship of occupation and identity.

Accommodations versus Modifications

The question of how best to adapt the traineeship requirements to maximize Kendra's successful participation was a constant challenge that was evident in the data. When *accommodating* a student, the curricular requirements are maintained but the method the student uses to meet them may be altered. *Modifications*, by contrast, alter the curricular requirements from the standard used for the rest of the students.

My ongoing struggle with providing accommodations as opposed to modifications for Kendra's cognitive and motor functioning was strongly evident in the data. When I first met Kendra, we discussed the accommodations she had for writing in her undergraduate program, which included an assistant to take notes for Kendra in her classes. As an enrolled student, Kendra accessed this and other accommodations through her undergraduate university's disability services department. However, she did not have access to the university's disability services department during this traineeship (because she was auditing the graduate-level course, she was no longer an enrolled student). As Kendra's coach, it might have been my role to take notes for her; however, I was also her teacher for the course so taking notes for her in class would have been inappropriate.

My experience as an occupational therapist stimulated a discussion of adaptive services among Kendra, her mentors, and myself. I asked Kendra about the possibility of using voice-to-text software to facilitate her typing. Despite my and others' constant

endorsement of this assistive device, Kendra was resistant; later, I learned that her hesitation came from a negative past experience with the software. I suggested audiotaping each training event, but some faculty objected due to the sensitive information shared in the leadership workshops about specific cases. Kendra came up with a solution on her own: she decided to purchase an electronic tablet. Its on-screen keyboard, portability, and adaptive features for her poor fine-motor skills made this the optimal solution. Kendra's first correspondence from the tablet was sent on August 2, 2010: "HI [sic] everyone, [The tablet] is great for me to use!" She performed all required assignments on this device.

In the beginning of the study, I frequently modified Kendra's curricular requirements. Her first assignment, a case brief, was not completed to the stated standards and would have warranted an immediate "Low Pass" if not "Fail." I emailed Kendra's mentors on September 23, 2010 to discuss my internal struggle with how to grade Kendra's work:

I wanted to share with you Kendra's case brief that she compiled for her group for Case 1. I'm not sure what feedback to give because it really was not done in the way that we expect them to be...My first thought about Kendra's document is that she turned in the assignment, regardless of whether it was actually done... Maybe I was not clear enough in my explanation. However, I know that I am consciously being lenient because of her disability, and that seems wrong...Do we make exceptions for quality because of disability?

One of Kendra's mentors, a special educator, guided me in the direction of accommodation rather than modification with this reply:

The [postsecondary education] model for students [with DD] is generally audit¹³ of a class with appropriate individualized accommodations... we would not be making an exception for her, so much as an adjustment that is indeed based on disability.

From this point forward, I reset my expectations to the same standard that the other students were expected to meet and offered accommodations to Kendra. When I told her that I would hold her to the same standards as the other students, she received this information gratefully. Still, when Kendra received a lower grade on a brief than she had expected, she had mixed emotions. She was upset about the lower grade but still sincerely appreciative of my resolution to treat her equally. The excerpt from my journal entry on April 13, 2011 reflects our conversation:

Another emotional part of our conversation was when I told Kendra that I graded her just as I would any other student. I did not grade her based on her improvements from last semester because I don't grade any student that way. She said she was glad I was honest with her—she wanted me to do that and she knows I was supposed to that. She said everyone has always sugar coated everything for her in the past and she did not want any more of that 'sugar coated crap'. So while I feel good that I held Kendra to the same standard as everyone else, the grade result was still hurtful to her. But, more importantly, the precedent put her in the same

‘class’ as everyone else and that made her feel good overall. So maybe both of us have made a difference...

Expectations

Kendra’s expectations of the traineeship were socially constructed, beginning at the moment she first learned about this postsecondary opportunity. CIDD faculty who knew Kendra approached her about piloting the traineeship for students with DD, thus giving her information with which she would shape her expectations. Kendra eagerly accepted the position as the first trainee with a DD because she expected a groundbreaking experience in the field of postsecondary education for students with disabilities. She also expected that the program would expand her role as a self-advocate. Moreover, Kendra had previously worked at the CIDD and had met former trainees. Having heard about some of their experiences, Kendra further developed her expectations to include interactions with other students at the CIDD, as well as leadership and training experiences similar to theirs.

When I met with Kendra in July 2010 upon her acceptance of the traineeship, she communicated these expectations to me. Having completed the traineeship one year prior, I was able to confirm that some of her expectations (e.g., interactions with graduate students and participation in service activities) were on point with what she would experience. Still, she did not appear to anticipate the academic and professional development demands of the traineeship. I talked with her about these components, thus contributing to Kendra’s socially constructed expectations for her experience as a trainee.

As Kendra immersed herself in the traineeship, she formed relationships with me (her educational coach and teacher), CIDD faculty, and other trainees and developed

expectations for each relationship. For example, Kendra expected me to support her learning with educational accommodations and/or modifications. Similarly, she expected her peers to guide and support her participation in the traineeship. Kendra's expectations of others, as well as how they met her expectations, impacted her experience of the traineeship. The data shows her frustration when key people did not perform as she had expected. A notable example occurred in April 2011, when Kendra seemed to expect me to modify rather than accommodate an assignment for her. Kendra emailed her assignment, a case brief, to me with an accompanying message: "Here is my Brief for case 4... along with a page of resources [sic] uses. I know I did much better [than last semester]. I worked really hard." My April 13, 2011 journal entry describes the events that occurred after I received her email.

I met with Kendra today about her brief from the transition case that she facilitated recently... I gave her a Pass as a grade—points deducted for length (it was about half a page and I wanted a page), references (there were no scholarly resources), and for content (she left out a lot of critical appraisals from her group process). [In our meeting] Kendra focused mostly on it not being 8 pages like last time. I was concerned about the lack of scholarly references. We discussed what a scholarly reference was and Kendra said she was aware of it. Is she just saying this because she doesn't want to admit that she might not understand? Well, if she knows what a scholarly reference is, then there is certainly no excuse... Kendra said that she was an English major in college so she felt extremely

upset that she didn't do better on this assignment. "I'm not going to take another class", Kendra said, "because I suck at it... I suck at being a facilitator."

When we discussed grading for the course, I reminded Kendra that I would grade her just as I graded everyone else (and also that this issue had arisen the previous semester with the same assignment). I did not grade anyone based on a comparison between semesters, so I did not do that for her. She was thankful for me not "sugar coating" my communication, but she was still hurt. After the meeting we both went to the class session, where a guest faculty mentor was presenting a case. Kendra introduced herself in front of the group as a trainee for one year, saying that "thankfully" she would not be doing it again next year. I presumed that Kendra's demeanor reflected her disappointment with her grade. She had a difficult time engaging in class that day from the time she walked in.

I got the impression from Kendra's email and from our meeting that she expected me to grade her according to the improvements she had made since the previous semester. Thus our interaction confused me because Kendra also said that she wanted to be graded like her peers. Kendra seemed to have expected the summary assignment to be modified for her, so she was clearly frustrated with my reaction to her final product. Our discussions about each of our expectations, which resulted in a mutual understanding, also resulted in a revision of Kendra's expectations for our relationship.

Kendra's trainee peers had expectations for Kendra just as she did for them. Kendra and the other trainees were part of a multidisciplinary team in which they collaborated on educational activities. While some trainees expected Kendra to perform

at a mediocre level compared to her peers because of her disability, others held her to the high standards set for other trainees. This variation in Kendra's peers' expectations shows that each trainee came to this experience with previously constructed values about the capabilities of people with DD.

Kendra's participation in the traineeship challenged the expectations of students as well as faculty members about the contributions that people with DD can offer in postsecondary education. Although Kendra might not have possessed academic skills at similar levels to the other trainees, she still contributed to the collective training experience by bringing the perspective of a person with a disability to group discussions. Her participation showed both students and faculty that learning was not only about academic performance but that learning also occurred because of the diversity of those involved in the educational experience. Working with Kendra affirmed that everyone had something to contribute to the group process. Many of the trainees came to recognize Kendra's involvement in the traineeship as valuable for their future work in DD. Her presence encouraged them to face inherent biases that they might have inadvertently veiled (e.g., the educational potential of people with DD). The traineeship was a social process in which shared experiences resulted in modifications of participants' expectations for people with DD in postsecondary education.

Balancing Lives

Kendra came to the traineeship with previously established identities. The data clearly showed her conflict over balancing these pre-existing identities with those that emerged during the traineeship. She titled one of her traineeship journal entries "Am I supposed to be Superwoman" to reflect the difficulty she was having with balancing

personal, professional, and academic demands. For example, as Kendra began the traineeship she identified as a self-advocate and a person with a disability, and these identities were noticeably prominent during class discussions as she jumped to advocate whenever an opportunity arose. Her interjections, which were passionate but also seemed condescending at times, alienated her from the other students and thereby impeded the development of her identity as a trainee. As the ultimate goal of this traineeship was for the trainees to supplement their current identities through the development of a (new) leader identity, we (me, her educational coach, and her faculty mentor) guided Kendra to curtail the exuberance of her advocate identity so she could focus on developing the identities of postsecondary student and leader without the confusion caused by overlap. She struggled immensely to do this at the beginning of the traineeship but worked at it throughout the academic year. By the end of the program, Kendra was able to better balance her identities of student, leader, advocate, and person with a disability.

Kendra also faced an additional challenge, that of balancing the demands of her personal life with her academic participation. When Kendra was having stressful experiences with her loved ones, she arrived for her traineeship with a negative demeanor and her performance suffered. My journal entry from March 2, 2011 describes a difficult encounter with Kendra following struggles with academic responsibilities and a personal issue with her boyfriend:

Today was a tough meeting... the questions [from the case] was written in multi-step format. For someone who has comprehension difficulties, this was overload. On top of that, her group facilitator assigned everyone two of these in-depth question to answer by

today... a daunting task for any student. And to pile it on even more, Kendra told me today that her boyfriend is moving away from NC and she doesn't know where he is going or if she will ever see/talk to him again. Essentially she has taken this as a break up...her boyfriend has been a pivotal figure in her life throughout this whole process...

It is unclear whether Kendra's issue with her boyfriend caused Kendra's academic stress or if the academic stress complicated her interpretation of her personal situation.

Analyzing the situation from a transactional perspective, however, the directional causation is irrelevant. Instead, it is important to note the dynamic interplay of people's various identities and "lives," and the dialectical relationship they have with occupation.

Pilot Study Conclusions

My pilot study affirmed that postsecondary education is a period of transition during which students increase their capacities for new occupational possibilities. The pilot study also solidified the value of a transactional perspective to the study of occupation and identity. The reader should note that I distinguish occupation and identity only for the theoretical purpose of analyzing each construct; in practice, the constructs are inseparable. Initially, I tried to focus my work with Kendra solely on her experiences at training events, but my field experiences revealed many more transacting factors in Kendra's experiences of postsecondary education. By the end of my pilot study, my data was informed by additional people in the social environment (e.g., peers, professors, and advisors), power structures (including those at the university and in the local city), and Kendra's own hopes for her future.

As this pilot study functioned as a foray into my dissertation research, it gave me the chance to implement qualitative methodology and a transactional perspective. I gained experience with interviewing and observations, as well as with modifying research strategies in the field as my data directed. Moreover, the process of interpreting this pilot study turned out to be instrumental in guiding the development and analysis of my dissertation research. It proved to me that occupational engagement and identity formation go far beyond the individual, both in theory and in practice. Accordingly, attention to socio-cultural factors of the postsecondary experience became critical to my dissertation research.

Chapter 5

Methodology

“We conduct our studies in order to examine how others manage the organization of their lives.” Harry F. Wolcott (2010, pp. 89–90).

Ethnography

Anthropologist Harry Wolcott (2008) defined ethnography as a method used by anthropologists and other qualitative researchers to study the behaviors of identified groups of people. Because the members of these groups are often characterized by common behaviors and settings, ethnographers look for the linkages among individual experiences as they occur within the larger social context of a culture. Based on his extensive background in qualitative research, Wolcott (2010) identified 12 attributes of ethnography. Most of his attributes support my chosen methodology but I have selected five to include in this dissertation. They are listed below, accompanied by descriptions of their application to my research.

Ethnography is holistic and sensitive to context. According to Wolcott, ethnographers “consider multiple causes and influences on our actions” (2010, p. 90). I began the current study with a blank slate on which to base my interpretations of the participants' actions. Although I had collected data from a postsecondary program in my pilot study, I was sensitive to the particular context of my dissertation research: a four-year, on-campus program for undergraduates with intellectual and developmental disabilities (IDD) who were experiencing postsecondary education for the first time. As

my data collection ensued, my repertoire of inferences grew. By the end of data collection I had a plethora of factors to consider when analyzing my findings about the participants' experiences.

Ethnographers use firsthand experience; ethnographers are the primary instruments of data collection. I established the methodological procedures of the present study to include myself as the sole data collector. My eyes and ears, my conceptualizations, and my relationships with the participants were the primary instruments utilized to gather data.

Ethnography is conducted in natural settings. I conducted all interviews and observations in the participants' natural environments so that I might witness the participants' lives in the most authentic manner possible. I used neither hypothetical nor controlled situations because I valued in-vivo data collection as yielding the thickest descriptions.

Ethnography is intimate. Wolcott portrays ethnography as an “intimate, long-term acquaintance” (p. 91). The time I allocated to data collection was just shy of one academic year, a sufficient time frame for fostering solid acquaintances with the participants, if not deeper friendships. I witnessed key aspects of the participants' experiences, such as classes and social events, and they shared their emotional journeys of positives and negatives with me. I would characterize my relationships with each participant as close.

Ethnography is adaptive. I realized this final attribute as I engaged in data collection and overhauled my methodology. Although I had initially positioned this project as a multiple case study, I noticed my focus quickly moving to the inner workings

of a culture rather than staying on the comparative similarities, overlaps, and differences of individual, bounded cases. The differences between case studies and ethnography, in general, can be difficult to discern. While the methods used could arguably be a collective case study by Stake's (2003) definition, consideration of the overall vision and the final product lend credence to this project as an ethnographic process (see Bailliard, Aldrich, & Dickie, 2013 and Schwandt, 2007). In fact, this very discussion of my methodological evolution is testimony to Wolcott's presentation of ethnography as adaptive. My research process corroborates his proposition that ethnographic research designs and questions are flexible; both may change once the researcher immerses herself in the field.

The process of converting this study's methods from a multiple case study to ethnography was not seamless. As a case study, I found myself floundering to express the richness of my data. I could enthusiastically communicate the data to my committee members, yet I struggled, through multiple drafts, to convey the richness of the data in a structured case report. The transition to ethnography was freeing—it gave me a forum from which I could recount stories of the students' engagement, thus vividly depicting their experiences in the truest way possible.

Ethnography is a fitting methodology for this project because of the transactional perspective that was utilized throughout its implementation. As Bailliard and colleagues (2013) explained, ethnography allows for emphasis on entire occupational situations because it accords special consideration to the relationships among situational elements. These may include, but are not limited to: environmental features, history and politics,

objects, people, and actions. Ethnography is flexible enough to contend with these and other elements that are constantly transacting and changing to influence situations.

As described in the chapter on positionality, I acknowledge that this research is not without my own influence. This understanding supports Bailliard, Aldrich, and Dickie's (2013) assertion that the ethnographic researcher is a co-creator, with the study participants, of the situation. Moreover, the authors maintained that participants influence how data is collected. As I became more familiar with my participants' preferences and ways of communicating, I learned that observation was a more effective method of data collection than semi-structured interviews were. Participant observations allowed the participants and me to talk freely about their experiences as they occurred. By contrast, I found that the participants had difficulty communicating their past experiences and feelings in the semi-structured interviews.

Guiding Questions

As initially proposed, the current study was guided by four multifactorial research questions that were based on the state of literature and research on postsecondary education for students with IDD in occupational science, occupational therapy, and related disability fields. In accordance with Wolcott's (2010) description of ethnography as flexible and adaptive, the questions for this study evolved throughout the process. The questions that most accurately reflect the intentions of this research are:

- 1) What are the dynamic factors that influence engagement in postsecondary experiences for people with IDD? This question is explored in this dissertation through a transactional perspective, with the intentions of discerning the various factors involved in

the students' engagement in postsecondary education and interpreting the relationships among those factors.

2) How do people without disabilities who are affiliated with the program (including students, teachers and administrators) contribute to the occupational engagement of the students with IDD? This second question ties into the first, as people other than the primary participants are undoubtedly influential factors of the occupational situation.

3) What is the relationship of postsecondary education occupations and student identities for a student with IDD in a postsecondary program? As discussed in the literature review, identity is a salient aspect of the college experience; thus, this third question explores the dynamic relationship of occupations and identities of the primary participants and builds upon the findings from the pilot study that evidenced the close occupation-identity relationship.

Study Approval

This study was granted initial approval by the University of North Carolina non-biomedical Institutional Review Board (IRB) in August 2011 (Study # 11-1547). Approval was renewed in August 2012.

One unanticipated event, a participant's guardianship status, was communicated to the IRB in April 2012. This participant was enrolled in the study in October 2011 with the understanding that she was independent and served as her own legal guardian. However, it came to my attention in March 2012, through casual conversation with this participant's instructor, that she might not be her own guardian. I immediately followed up with my site contact, who confirmed that she had been mistaken about this

participant's guardianship status. I discussed the situation with the participant and, with her approval, contacted her mother via telephone. The participant's mother affirmed her support of this project and verbally consented for me to use all of her daughter's data from enrollment until the end of the study. I then communicated the unanticipated event to the IRB and proposed use of a parental guardian consent form. The IRB determined that no additional information was required and no changes to the study were warranted (including the parental guardian's written consent).

Participant Criteria and Recruitment

The primary participants for this study included 10 college students with IDD who were actively enrolled full-time in a university-supported course of study, Making Strides (MS).

Inclusion criteria. This study was open to students between the ages of 18 and 28, to reflect the bulk of the American demographic of full-time college students.¹⁴ All students were required to be legally independent, meaning that they did not have legal guardians.

Exclusion criteria. Individuals were not eligible for participation in this study if they were enrolled less than full-time in the MS program or if they were under 17 years of age or over 28 years of age.

Initial contacts, referrals, and secondary participants. I utilized a gatekeeper (an MS staff member) to make initial contact with students in the program who met the inclusion criteria and who she thought might be interested in participating. The gatekeeper worked closely with the students and knew their guardianship status. As I initially requested, she identified eight participants, including two students in each

academic year (freshman through senior). Eventually, when I decided to enroll additional participants, the gatekeeper referred two more students. Secondary participants contributed to this study through their presence during interviews and observations. They included friends of students, support staff, teachers, and other people associated with the primary participants. All data from secondary participants were anonymous and general in nature.

Data Collection: Interviews

I conducted in-person participant interviews at enrollment and throughout data collection. Each interview was tape-recorded with the participant's consent and then transcribed. Handwritten notes taken during the interviews were also transcribed. Overall, 22 different types of interviews took place during this study, resulting in 224 pages of transcribed interview data.

Initial interviews. Initial interviews were administered during the first meeting after the participants signed the consent forms. The purpose of these semi-structured interviews (SSIs) was to collect demographic information as well as to obtain knowledge about each participant's life goals, decision to pursue postsecondary education, transition to postsecondary education, feelings about being a student, and future plans. Each initial SSI lasted approximately one hour.

Recurring ethnographic interviews. Bimonthly open-ended SSIs were conducted during the first semester of data collection to check in with the participants about any significant events that might have occurred since their previous research visit. Less structured than the initial interviews, these SSIs were similar to friendly conversations about the participants' activities. They explored the students'

postsecondary education activities, the influences of current experiences on their future plans, and their feelings about being students. These SSIs were developed for semimonthly administration, with the option of modulating this frequency depending on the data generated from them. Each interview lasted between 30 and 90 minutes.

As anticipated, semi-structured recurring interviews were slowed and then ceased by the middle of data collection because participant observations yielded richer data. Unlike the abstract discussion of events that had already occurred by the time interviews were administered, participant observations gave the participants and me opportunities to talk about events as they were happening. In essence, the participant observations lent themselves to open-ended “conversational interviews.”

Interviews of secondary participants. An additional SSI was developed to ask secondary participants general questions about the MS program and students with IDD on campus. The interview did not pose questions about specific primary participants with whom the secondary participants interacted. No semi-structured secondary participant interviews were collected, because I felt that I was able to collect sufficient data about the MS program and about the secondary participants’ involvement with the program and primary participants during the observations.

Data Collection: Participant Observation

Naturalistic participant observations of the students occurred regularly in classes, at their off-campus apartments or houses, and in the community, in order to learn about cultural practices and daily life. I asked the participants to continue their typical routines and activities during observations, and often partook in the activities to minimize artificiality of the environment and to try to explore the experiences from the

participants' perspectives. Phone calls, emails, and unplanned conversations (e.g., when seeing a participant outside of a scheduled observation) were also included in the observational data. Fieldnotes were written during the observations or immediately afterward, and then transcribed.

An observation guide was utilized as needed to facilitate data collection. Observations ranged from 30 minutes to four hours. I conducted 121 observations during the course of the study, resulting in 212 pages of transcribed data. This figure includes nine occasions of phone or email conversations with various participants.

Data Collection: Acquisition of Supplemental Programmatic Information

I collected supplemental information about the history and programmatic practices of MS through the program's website and three informal interviews with MS program administrators; the latter yielded an additional six pages of transcribed data. During the interviews, program administrators provided me with many of the materials that MS students, parents, and staff received. The director of academics gave me copies of the MS course catalogue (including course descriptions) and the master course schedule for both semesters of the 2010–11 academic year. The director of academics also shared the anticipated plan for the MS students' requisite courses in the upcoming 2012–13 academic year; this plan included the fall 2012 master schedule as configured at the time of our meeting. Information about the upcoming academic year provided helpful insights about how the program would be changing. The director of student life gave me copies of the student-life support packages (e.g., supplemental supports offered to freshmen and sophomores outside of class hours), the student-support plan agreement that outlined tiers of support and costs (to be signed by the MS student, his or her legal

guardian or a family member, an MS staff member, and the MS executive director), and a sample freshman student-life progress note that identified skills related to each freshman course.

In addition, I attended an information session for students who were thinking about applying to the MS program. The session I attended in February 2012 was comprised only of prospective MS students and their families, although the executive director of MS told me that these sessions were typically integrated with sessions for prospective degree-track students. The executive director suggested that prospective degree-track students might not have attended because the deadline for the university's application process for the 2012–13 school year had already passed. The MS application deadline had recently passed as well, but the executive director explained that prospective MS students and their families often begin collecting information about colleges earlier than their degree-track peers. Therefore, attendees of the February 2012 information session may have been seeking information about applying for a place in the 2013–14 freshman class, rather than the 2012–13 class. The information from this information session yielded four additional pages of transcribed data.

Data Analysis

Data analysis was an iterative process that took place throughout the study period and was informed by data collection. I implemented qualitative coding for the data analysis methodology, a process I based on Wolcott's (2008) notion of "cultural patterning." According to Wolcott, "ethnographers look for how people in their ordinary circumstances behave in more-or-less similar ways..." and describe cultural patterns as "customary ways of behaving and customary reaction to the behaviors of others" (p.

244). I looked for these ways of behaving and interacting in the students' occupational situations; the culture, of course, was the culture of the MS program. Codes describing the occupational situation and the MS culture emerged as data were generated. Individual codes were organized into coding categories when all data had been recorded. I independently coded all fieldnotes and interview transcriptions using qualitative research coding software (ATLAS.ti). Peer debriefing with my dissertation chair (Humphry) occurred regularly throughout the process in attempt to minimize researcher bias.

In total, 65 individual codes were developed. Of these, 14 were purely organizational: 10 were named so as to distinguish the primary participants, and four were used to label each class by year (i.e., freshman, sophomore, junior, senior). Overlaps among the codes were noted in my coding dictionary so that I would recognize potential instances of cross-coding (e.g., Social Engagement and Inclusion/Acceptance, and Self-Determination and Advocacy). The codes were divided into the following coding categories: Participants, Identity, Context, Occupation/Experience, and Transition/The Future.

The Study Location

The state of North Carolina offers nine postsecondary education opportunities for students with IDD (Carolina Institute for Developmental Disabilities, 2013b). Five of these opportunities are located at community colleges and one is year-long traineeship in self-advocacy at a state university (the program in my pilot study). Of the remaining three programs, all of which operate at four-year universities, only MS offers a four-year certificate program that mirrors the experience of students without disabilities. I selected MS for my study because the four-year certificate and campus experience most closely

resembles the traditional college experience for young adults in postsecondary education. I also had to consider the programs' proximity in my decision, because the three university programs are dispersed around the state. MS was the closest university program; the other two were at least 100 miles from my home. Negotiating this distance would have created a logistical problem for data collection.

According to the MS program's website, the mission of MS is to prepare students to be self-determined individuals who live and work in the community. Students in the MS program are young adults with IDD who attend the university as full-tuition, full-time students. Although MS students take part in a university-recognized course of study, MS instructors are employed through the program's partner nonprofit organization rather than by the university. The students attend a variety of classes on the university's campus, including segregated core courses (available only to MS students) and inclusive electives (with degree-track students). All MS courses are graded for credit, but MS students are given the option of taking electives for credit or audit. MS students receive a university-awarded certificate upon completion of the course of study's graduation requirements. The MS program's partner nonprofit organization supports the students' academic, personal, and campus experiences by providing the university with educational instructors to implement the course of study, as well as support staff for the students as they navigate the college experience and transition from college to life after graduation.

Making Strides is the oldest postsecondary education program in North Carolina for students with IDD. Its established history and ongoing development were additional factors in my decision about where to locate this study. The program was officially started in 2006, and the first students officially stepped foot onto the university campus in

2007. The first graduating class of six students received their certificates of completion in 2011.

Primary Participants

The participants are described in this section through short biographical sketches. Pseudonyms are used to protect their anonymity. Descriptions of each participant are based on how I came to know them over the course of data collection, as well as on interview and observational data.

Allison. Allison was a freshman. She was initially skeptical about school, especially because it meant being away from her parents, dog, friends, and boyfriend. Due to her limited mobility she faced physical accessibility obstacles; these often restricted her social activities (e.g., chatting with her classmates as they walked from one class to the next). Allison lived in an off-campus student housing apartment complex, Green Ridge (GR), with another student in the MS program.

Allison was in the process of navigating college life and determining how she fit in at the university. Although she had many ideas for her life post-college, she was not convinced that college was the right way for her to get there. Allison's parents were supportive of her transition. "[They told me] if I stayed at home all my life I wouldn't be, you know, successful and happy," she said at our initial interview. Allison's geographic distance from the few postsecondary education programs in the state necessitated her relocation for college.¹⁵ She struggled with being in a new environment, away from the safety of her family and friends back home.

Sean. Sean was a freshman. He lived in GR with a family friend who was also in the MS program and spoke excitedly to me about many aspects of school: classes (core

and electives), social life (dating and parties), and campus activities (sporting events and religious clubs). He was a strong disability advocate whose personal mission was to show university students and the greater community that having a different ability did not automatically infer limitation.

Sean enjoyed being in college but wished that a similar program might open at the larger state university near his hometown, where many of his friends went to school. He aspired to get a graduate degree in music from that university. When I asked Sean about his decision to go to college, his response reflected a self-determined strategy:

I decided to go to college so I can try to focus on my music major.

The only reason that I chose [Making Strides]—this will be a good one—is because I couldn’t get into [this university as a degree-track student] and I couldn’t get into [the hometown university that I wanted to go to]. I would have to take—go to community college first and then take the SAT. The only reason why I didn’t choose to go to [this university as a degree-track student], like the other side, is because I want to learn living skills. It’s a good thing to learn, so, I said “Let me go to [Making Strides] first, then I can focus on one of my majors and learn some living skills, and then I can graduate and then go to [the hometown university that I wanted to go to].”

Sean’s parents, who were strong supporters of his educational successes, had found MS during their own research and subsequently informed his high school about the program. Sean’s parents advocated for Sean’s transition plan to include postsecondary

education as a goal, and they helped Sean make that goal into a reality by facilitating his transition to MS. Sean appreciated his college experience as a transition to adulthood.

Matt.¹⁶ Matt was a freshman. He enjoyed being around his same-age peers and doing typical college activities with his friends (e.g., partying and playing sports). Matt lived in GR with one student in the MS program and one degree-track student from the university. Despite many people telling him that he was not ready for postsecondary education, he was determined to learn anatomy and physiology in preparation for a career as a personal trainer. In our conversations he referred to a 2011 graduate from the MS program who had achieved his personal trainer's license after much hard work and dedication.

As a freshman, Matt had a structured schedule of core classes. He ardently opposed the all-day schedule, saying that it was “not like what real college students do.” He felt that MS was hindering his social experiences because it packed his school schedule, which prohibited him from committing to student activities such as sports teams. Matt also felt that he was unchallenged in his core classes and was not learning what he wanted to learn from them. He looked forward to sophomore year, when he might be able to take classes outside of the course of study. Still, Matt expressed enjoyment with the cooking component of his MS curriculum, which fed his culinary passion and improved his independent living skills. “I’m good at [cooking],” he told me.

Tory. Tory was a sophomore. She was informally recognized as the peacemaker of the sophomore class because she included everyone in whatever she was doing. Social and outgoing, Tory was an active participant in the university community who frequently

attended extracurricular events on campus with her friends and support staff. Tory lived in GR with another student in the MS program.

When I asked Tory about her decision to come to college, she told me that she came to college to learn. She was, indeed, devoted to her studies and frequently called home to tell her mother what she was learning in her classes. The transition to college seemed seamless for Tory. Her response to my question about whether or not she was a college student was an emphatic “Of course!” Tory described a college student as “following your hopes and dreams and future.” She hoped to become a singer and to marry her boyfriend.

Annie. Annie was a sophomore. She greatly valued her relationships with family and friends, including her close friendship with Tory, and her relationship with her boyfriend (also a sophomore). Annie enjoyed her connection to others through social media. She told me that she loved to take pictures and post them on a popular social networking site, a passion that drove her ambition to be a professional photographer.

Annie’s school responsibilities were just as important as her social networks. She strived to get As in all of her classes, and expressed commitment to becoming a stronger student in college than she had been in high school by studying more and being focused. Annie defined a college student as someone who did homework, studied, and was on time and prepared for class. She lived at GR with a degree-track student from the university, but because that student was never present during my times with Annie, it seemed to me as if she lived alone.

Chip. Chip was a junior. He was proud that his academic performance had placed him at the top of his class. Chip interned at a local food business and also volunteered at

the local animal shelter. He spent his leisure time walking around campus, reading in the library, and watching movies in the apartment clubhouse theatre from his large personal collection. He lived with two degree-track students at an off-campus student housing apartment complex, West Knoll (WK).

Chip came to college in order to gain skills for a career in appliance mechanics. He knew many people who went to college, notably peers from his church. Chip likened the characteristics of a college student to his former peers in the Boy Scouts: they should be helpful and trustworthy. He described college student activities as making friends, socializing, and preparing for a future career.

George. George was a junior. Despite his self-proclaimed “allergy to mornings” that caused him to struggle with his academic coursework, he excelled in his internships and life- skills courses. George greatly valued the living skills he learned in MS because he feared being relegated to a group home after graduation if he could not manage his diet and medications. He even yearned for the day when he could pay his own phone bill. George suggested that college was an opportunity for personal growth in independent living and self-determination.

George expressed content with living away from home by himself in his off-campus apartment, although he also mentioned missing his parents. Mostly he missed sport-shooting with his father, although they participated in this when George returned home from school. George enjoyed the outdoors and hoped to build a career in gun maintenance.

Benjamin. Benjamin was a junior. Because of his deep attachment to his mother, he looked forward to moving home after graduating to take care of her and her house.

Still, he felt strongly that going away to college was the right path for him and had explained to his mother, “[T]his is what I have to do.” He lived in GR with two roommates who were both in MS.

Benjamin spoke excitedly about getting his driver's license someday, after college. He saw his license as a positive step toward a potential career in truck driving (his father's profession). He also pondered working with snakes in a park system near his home because he was gaining experience with reptiles in one of his internships. Having not yet determined his future direction, Benjamin said that he lived “one day at a time, one year at a time.”

Claire. Claire was a senior. Incredibly outgoing and social, she knew everyone in MS and everything that was going on with them. Claire intermittently dated another participant, Zachary, throughout the course of this project. She lived alone in a duplex near campus but had family in the area who were available to support her when needed. Claire's mother lived hours away. Despite this distance, Claire planned to stay in the university area after graduating because she had established her life there.

When asked why she decided to go to school, Claire responded: “To make new friends and do good things that I can do in college... like finance” and added that she came to college to have new relationships. Claire's definition of a college student was “having your own ways you can do [things]. You can change a lot.”

Claire had many goals that she hoped to achieve during and after her time in MS. When I first met Claire, she told me that her goal was to be a writer; at the time, she was working on an article for the school magazine. If being a writer did not work out, Claire said that she would consider opening a home-manicure business after college. Claire also

dreamt of becoming a famous singer, dancer, and actor—a set of aspirations that she and Zachary shared. They often compared themselves to and pretended to be the lead characters of their favorite movie.

Zachary. Zachary was in the senior class, although technically he was a junior (his parents felt he needed more time in the MS program due to his struggles with academics). At the time of this research, Zachary was confident that he was getting back on track to graduate. He spoke fondly of his high school memories, social life, and a job that he enjoyed. Zachary lived in GR with two other students who were also in the MS program.

Like his girlfriend, Claire, Zachary wanted to be an actor and singer. He told me that he went to college in order to meet new friends and have “new experiences.” Having graduated high school with honors, Zachary implied that college was the next logical step for him. Many of his high school friends had enrolled in colleges around the state. Being a college student was a salient identity for Zachary. He showed me his student identification card during our initial meeting, beaming as he explained that it was his pass to college sporting events, concessions at the student union, and campus transportation. He was also quite active in the university’s pep club that cheered at all home games. Zachary defined a college student as someone who was enrolled and went to every single class, adding that he did not like that part.

This chapter has described the methodology used for data collection and analysis in this study. A brief introduction to the MS program and the study participants has been provided. The next chapter will further describe the culture of the MS program.

Chapter 6

Making Strides: A Closer Examination

Making Strides (MS) is a four-year academic program associated with a public university in North Carolina. This chapter presents the background of the MS program, followed by an in-depth report of how the program structures academic and student life activities for its participants. The students' engagement in college experiences are situated through discussions of the contextual factors that transact to compose the occupational situation. This chapter contains a theoretical interpretation of MS based on Holland et al.'s (1998) concept of figured worlds, which I use to show how MS is situated within the figured world of postsecondary education for students with IDD, as well as how participation in the figured world of postsecondary education by students with IDD impacts the MS students' occupational engagement and identity development. The chapter concludes with an experience-based lexicon of the MS culture. Key terms from the MS culture are introduced throughout and discussed with reference to practical examples from the data.

History of Making Strides

MS's executive director explained to me that MS began as a grassroots organization within North Carolina's mental health network and that its initial aims were to provide transitioning high school seniors with options other than group homes and sheltered workshops. A local parent of a child with special needs donated seed money to MS that provided sufficient resources for the program to open in 2006 with eight students. At the time that data collection was initiated for this study in 2011, MS had

grown to approximately 38 students in the four cohort classes of freshmen, sophomores, juniors, and seniors. The students ranged from 17 to 29 years old with an average age of 22 years.

Initially, MS was a service organization on the university campus. As the program grew, it became incorporated with the university such that its academic offerings were recognized as a university course of study. Eventually, through provision of academic instruction and student-life support (SLS) staff, MS became a private nonprofit agency in partnership with the university—a structure that structure allows for in-house case management. The program director explained that this approach has reduced reliance on outside services, thereby simplifying the case-management process; however, MS students still have access to external service providers as needed. For example, Benjamin met with a local case-manager as he prepared to transition out of the MS program.

Eligibility for the MS Program

MS students must be at least 18 years of age and have a documented diagnosis of an intellectual disability. Students must have finished secondary education (MS is not a dual-enrollment program), possess basic personal care skills, and be able to live in student housing without supervision. They may not exhibit behaviors that are harmful to themselves or others, or have a history of arrest or probation. MS students cannot be academically eligible for acceptance to a degree-track program of study in the affiliated university. Families must be supportive of their students' efforts to participate in the MS program.

Paying for MS

State funds for mental retardation and developmental disabilities initially covered the cost of program tuition. As MS became a recognized course of study, students and their parents gradually became responsible for this cost. At the time of this study, students and their families were responsible for paying full-time university tuition at the same rate as degree-track students. Federal financial aid had not been established for MS students at the time of this study.

MS offers supplemental student-life support packages to MS freshmen and sophomores. These packages provide assistance with home management, hygiene, socialization, accessing campus resources, and other non-classroom aspects of the college experience. The packages range in price according to the intensity of support. The director of student life explained that students and their families pay privately for these services; however, students may receive state funding for student-life support if they meet North Carolina's conditions for specialized care for people with IDD (NC Department of Health and Human Services, 2013). Such cases are extremely rare, however. Only a handful of freshmen qualified for state funding at the time of this study; all other students and families paid privately. According to the director of student life, these supplemental services can cost up to \$40,000 annually in addition to tuition.

Academics

Students in MS receive a four-year interdisciplinary education that culminates in a university-recognized certificate in Integrative Community Studies (see Appendix B for the MS course catalog and Appendix C for the course-of-study schematic). The curriculum for freshmen and sophomores focuses on independent living and introductory

courses in advocacy, finance, and community engagement. During their sophomore year, MS students select a concentration (e.g., business development or civic engagement) that will guide their advanced coursework. The junior/senior curriculum focuses on independent living, career preparation, and advanced courses in advocacy, personal finance, and the selected concentration. At the time of this study, freshmen and sophomores were required to take 21 credit-hours of classwork each semester. Juniors and seniors had fewer hours of group classes, but greater emphasis was placed in their classes on the practical application of work and life skills in the community.

MS students have the option of taking electives with degree-seeking students, for credit or audit, in some other university departments (Communications, Media Studies, Therapeutic Recreation, Art, and others). They are responsible for fulfilling any prerequisites prior to enrollment in such electives. In addition to these further learning opportunities, the director of academics explained that the MS students' participation in electives facilitates relationship-building and inclusion with faculty and students across the university. By the spring of 2012, the MS program's director of academics was proud to report that more academic departments were accepting MS students into their courses than ever before.

Unfortunately, not all academic departments welcome MS students to audit their electives. The director of academics described an ongoing struggle with one particular department that opposes MS students auditing its courses because their presence is thought to reduce the number of degree-track students taking the courses for credit. This example of faculty resistance mirrors the institutional barriers that Causton-Theorharis et

al. (2009) discovered in their survey of personnel from postsecondary education programs for students with IDD.

Graduation. The MS program holds a private commencement ceremony each year for the graduating seniors. This ceremony includes speakers from within the MS program and across the university, presentation of certificates, acknowledgement of the student who achieved the highest grades, and an on-campus celebratory reception. MS administrative staff are hopeful that someday the university will include MS students in the university-wide graduation ceremony, but for the time being it is university procedure that students who complete certificate programs do not participate in this commencement. Because of this protocol the MS students are excluded from the typical celebratory culmination of the college experience, even though they spend four years on the same campus as their degree-track peers. Nonetheless, the MS students are denied university-wide graduation due to university bureaucracy rather than outright discrimination. This exclusion function can even be likened to inclusion, in the sense that MS students are subject to the same procedural practices that are applied to students without IDD who are enrolled in the university's other certificate programs.

Student Supports

MS provides support for students' activities outside of the classroom to ensure they receive a well-rounded college experience. The program provides two levels of student-life support staff: student-life supports and student-life advisors. Student-life supports are degree-track undergraduates who provide the paid services that are featured in the student-life support packages for freshmen and sophomores. These supports focus on social engagement, campus involvement, and independent living (see the end of this

chapter for further description of student-life supports). Student-life advisors are typically college graduates who have previous experience working with people with IDD. Student-life advisors work with MS juniors and seniors to facilitate their transitions out of college. This type of support includes independent- living skills and career planning. Because support from student-life advisors is built into the MS curriculum, no extra cost is involved.

Student Housing

Any student who wishes to reside in a campus dormitory must enter the university's lottery system. At the time of this study, there was a shortage of dormitory living options for all university students, including those in the MS program. Still, MS students were encouraged to live in student housing, such as the off-campus student-apartment complexes that are within walking distance to the university. All but two of the students in this study lived in off-campus student housing at either one of two popular apartment complexes near campus; one student lived in a duplex just down the street from one of these apartment complexes and the remaining student lived in an apartment that was an approximately five-minute drive from campus. Most of the participants lived with other students in the MS program, whereas a few lived alone or with degree-seeking university students.

Student Identification Cards

In addition to the barrier of faculty resistance described above, Causton-Theorharis et al. (2009) identified impeded access to student identification cards as an additional institutional barrier to engagement in postsecondary education for students with IDD. MS administrators had only recently resolved this issue by the time I initiated

data collection in the fall semester of 2011. This was a great achievement for the program because it allowed the MS students to feel like true college students: with cards, they had access to campus sporting events and the student recreation center, and could purchase food on campus (with the debit-card function). Three of my 10 participants proudly presented their student identification cards to me in their initial interviews when asked if they considered themselves to be college students.

Situating the Occupational Experience

Contextual factors transacted to situate the MS students' engagement in the college experience (see Cutchin & Dickie, 2012; Dickie, Cutchin, & Humphry 2006; Hocking, 2000; Huot & Laliberte Rudman, 2010). The methodological redevelopment of this project from a multiple-case study designed to focus on individuals into a more holistic ethnography allowed me to effectively account for the contextual factors that were dynamically influencing the students' occupational situations. These contextual factors are considered below.

Of paramount importance was the novelty of college occupations for students with IDD. Although they were engaging in occupations similar to those of college students without disabilities (e.g., taking classes and participating in campus activities), the stark contrast of their current occupational engagement to the historical context of people with IDD (i.e., as segregated and alienated) rendered these occupations innovative. The students in MS were trailblazers. They were among the first people with IDD in the United States to engage with college occupations and especially with the occupations at a four-year university. In essence, the college occupations observed in this

study resulted from the functional coordination of college students with IDD who were completing actions that, historically, had been reserved for people without IDD.

Social context has been depicted as influential in shaping occupation (Humphry, 2005); yet, I also found occupation to be influential in shaping the social context of the MS program. For example, the MS students' occupations seemed to unite them in a common community. They came to support one another and to share common values through student activities such as going to class, attending social events, and dealing with schoolwork. Furthermore, engaging in student occupations elicited a common lexicon among the students. Concepts such as advocacy, self-determination, and independent living may have been understated in the population of university students without disabilities, but they were frequently expressed in these participants' academic and casual conversations. These findings support the conclusions of Bratun and Asaba (2008), who conducted an ethnographic study of Qi Gong practices¹⁷ in order to explore how occupation facilitates community establishment. The authors noted that the Qi Gong occupation connects practitioners through shared interests and interactions, and emphasized that this expression of community transcends physical boundaries and is more appropriately described through social relations. (For further discussion of communities as occupational, see Christiansen & Townsend, 2004).

The physical environment has long been considered to be the context in which activities transpire. However, occupational scientists implementing a transactional perspective have challenged this notion, arguing that individuals do not act within their environments but rather with them (Cutchin, 2004; Cutchin, 2007; Cutchin & Dickie, 2012; Dickie, Cutchin, & Humphry, 2006). For example, in their consideration of identity

formation in the wake of changing places and routines, Huot and Laliberte Rudman (2010) posited that changing places leads to changing routines and thus necessitates changes in identity. I liken this study, which concerned migrants, to the current study's population because my participants' transition to college yielded new routines and new identities. Fundamentally, college student occupations are "college" because (at least in part) of the transactions of students as they engage with their campus environment. In this case, the campus environment offered the students access to new occupations (e.g., eating at the student union and attending classes in campus buildings) that would not be available to them if they were not students at the university. My research confirmed that environmental factors should be considered as elements of occupational situations, rather than the physical context being defined as an abstract container in which situations occur.

Postsecondary Education for Students with IDD: A Figured World

In their seminal work, *Identity and Agency in Cultural Worlds* (1998), anthropologist Dorothy Holland and her colleagues presented the concept of figured worlds and described them as socially produced, culturally constructed realms of action that situate identity:

Figured worlds take shape within and grant shape to the coproduction of activities, discourses, performances, and artifacts.

A figured world is peopled by the figures, characters, and types who carry out its tasks and who also have styles of interacting within, distinguishable perspectives on, and orientations toward it.

(p. 51)

Figured worlds are fluid and flexible; they can change over time. Members learn and adapt practices as they participate in the figured world's everyday routines. Also contributing to the ongoing development of figured worlds is members' participation in other figured worlds. Holland and her co-authors explained that people are part of various figured worlds; as such, they transfer elements of participation among them.

Postsecondary education for students with IDD can be interpreted as a figured world according to the definitions and examples offered by Holland and her co-authors. Membership includes students as well as support staff, teachers, and administrators. There are shared activities and performances (e.g., classes, program events, and other student activities), discourses (e.g., disability history, goals, grades, and language that describes the postsecondary experience), and symbolic artifacts (e.g., student identification cards). The values of self-determination and self-advocacy infuse members' actions with meanings, for example the challenge (specifically in postsecondary education) to historically and culturally low expectations for people with intellectual and developmental disabilities. Finally, members of the figured world of postsecondary education for students with IDD also participate in other figured worlds (in other words, they are also university students, faculty and staff, and members of local disability societies).

The figured world of postsecondary education for students with IDD is lived through the local space of practice that I identify as the MS program. The MS program is one of many postsecondary programs, which we can also think of as local spaces of practice, within the figured world of postsecondary education for students with IDD. Members of MS enact aspects of the figured world of postsecondary education for

students with IDD on a microcosmic level that is culturally specific. For example, shared activities include classes and social events specifically for MS students; cultural discourses include the history of the MS program and rules for attending class; and artifacts include a written-out, student-directed plan of support and a university-recognized certificate in Integrative Community Studies.

Living identity through figured worlds. In their description of the dialectical nature of identity and agency, Holland et al. (1998) likened behavior to a “sign of self in practice” (p. 31). Interpreted according to the discourse of occupational science, this description can be related to occupation such that occupation is part of the situated practice of the self. In addition, people form their identities through participation in figured worlds. As Holland and her co-authors wrote, “Identities are improvised—in the flow of activity within specific social situations—from the cultural resources at hand” (p. 4). The authors further explained that “identities are lived in and through activity” (p. 5) and referenced Holland’s ethnographic study of female students in American universities to elucidate this point (see Holland & Eisenhart, 1990). Although originally designed to investigate how peer groups influence career, Holland and Eisenhart discovered a figured world of romance whose members participated in self-beautifying activities and other relevant social discourses in order to increase their value within it, and also to develop the identity of an attractive female. This study, in addition to the other case studies in Holland et al.’s collection on figured worlds, demonstrates that, in essence, people “do” figured worlds. The students in MS lived the figured world of postsecondary education for students with IDD through engagement in student occupations. They engaged in

occupations that would portray their student identities, and they also engaged in occupations that further developed their student identities.

Holland and her colleagues further characterized identity as mediating past histories and present experiences. This characterization aligns with Cutchin and Dickie's (2013) transactional perspective that appreciates a holistic continuity of past, present, and future that connects person with context. The identities of MS students as postsecondary students with IDD were constructed from a history of dependence and alienation for people with IDD, the students' present experiences in postsecondary education, and the independent future that the students (and their parents and staff) wanted for themselves.

Enacting the Figured World of Postsecondary Education for Students with IDD: An Experience-Based Lexicon of MS

I end this chapter with four notable terms that made recurrent appearances throughout my observations and interviews. These terms reflect how the MS students and staff enacted the figured world of postsecondary education for students with IDD through the MS program. These terms were determined to be salient to the MS program because of their regular usage by MS students and staff. Instead of a dictionary-like list, I offer a lexicon built from this study's observation and interview data to guide the reader through the upcoming chapters.

Independence. During one observation, I observed the sophomores defining "independence" for a Dimensions of Campus and Community Living homework assignment. They worked on this assignment in study hall under the guidance of a different MS instructor who told them, "You know this one, you don't have to look it up." She then gave the students examples from their own practical coursework that that

illustrated independence: living on your own and taking care of yourself including money, health, and relationships.

In terms of living on their own and taking care of themselves, independence also meant that the students fulfilled these responsibilities without help from external sources. For example, I once asked Annie if she cleaned her own apartment or if someone did it for her. “I clean it myself,” Annie replied. Her friend immediately supplemented her response: “Be independent,” she stated firmly. In another example, Tory and Annie were excited to tell me that they had found a place to live in the upcoming year. “How did you find it?” I asked. Tory said that they used an apartment magazine and looked on the computer. Annie showed me the guidebook and then showed me the advertisement for the specific apartment complex. “We are very independent, right, Tory?” Annie proudly asked.

For George, independence was internalized as freedom from having to live in a group home. George frequently spoke in his interviews and during observations about his attempts to eat more healthily. He reported during his initial interview that he was trying to be healthy when eating at the student union, but it was difficult because the options were mostly unwholesome foods like pizza, cheese sticks, and soda. Although George struggled with a healthy diet throughout his participation in the study, it was of the utmost importance for him to safely make nutritious meals that would enable him to live independently instead of in a group home. “Two main reasons people go into group homes are because they can’t eat in a nutritious way and they can’t take their medication independently,” George’s instructor explained to me. “So we’re working on those two things.” George worked diligently with his instructor to learn how to develop healthy

grocery lists and meal plans. George also put effort into his medication management by working to master a timed medication device so that he could become independent with this task prior to graduation. “I don’t want to go live in a group home,” he asserted.

George’s anxiety about group-home living was not unfounded. In fact, his disability put him at a higher risk of obesity and medical issues that would potentially require close supervision (Rimmer & Yamaki, 2006; Sutherland, Couch, & Iacono, 2002). Studies of environmental settings and intellectual or developmental disabilities have found the restrictiveness of environments to be inversely related to medical problems such as obesity (Lewis, Lewis, Leake, King, & Lindemann, 2002; Rimmer, Braddock & Fujiura, 1993, as cited in Rimmer & Yamaki), which suggests that independent living may have negative implications for health compared to living situations that include greater supervision.¹⁸ MS’s facilitation of knowledge about and implementation of healthful lifestyles was preparing George (and the other students) for independent living .

Self-advocacy and self-determination. MS requires all students in the program to take courses in advocacy and self-determination during all four years (See Appendix B for the course catalog). Themes from these classes are integrated into other courses in the MS curriculum. For example, freshmen and sophomores are required to share current events in their weekly Dimensions of Campus and Community Living class. During one of my observations of the sophomore class, the instructor shared a news story about people with intellectual disabilities who had been kidnapped and tortured. He told the students that the victims were kidnapped because the criminals wanted the victims’ monthly government income. “Why did I think of you when I read this article?” the

instructor asked the students. “Because we have a disability,” one student responded. The instructor validated that answer and then added, “Also because you go to ____.” The class fills in his blank with “class” and “college.” “Yes,” the instructor said. “You are being proactive by learning to stand up for yourselves in your college advocacy class.”

Despite their overlaps, I learned to distinguish self-advocacy and self-determination from their intended consequences. Self-advocacy emerged as the act of communicating one’s rights. During one observation, Allison’s account of an experience with her home-health aide illustrated the definition of self-advocacy for me:

Allison complains about her home health aide not helping her in the shower last week. “She was on the phone the whole time,”

Allison says. “I told her she needed help and that I was going to call the agency to complain. The next day, I did that. I told the agency to fire her.” Allison says the agency fired that person and now she has new aides. “I was trying to be an advocate for myself... I told them to fire her and they did,” Allison says.

Self-determination seemed to be the act of expressing one’s control.¹⁹ I used self-determination in my fieldnotes to express instances of agency, such as when the students used their weekly meal planners to plan the meals they wanted and when they expressed what they wanted to do with their SLS. This idea of self-determination recurred throughout the data when contemplating how much control the students had over their daily routines (as opposed to how much of their time was structured for them by external forces).

The paradox of self-determination. I noted a paradox in the MS program's execution of self-determination because teachers encouraged students to make their own choices and stand up for themselves, yet the program frequently dictated how the MS students spent their time. This discrepancy in my data led me to question how the understanding of self-determination might be similar or different for MS staff and MS students. Matt, the freshman who lamented about the time constraints of the MS scheduling system during his initial interview, said that he did not feel like a college student because the structure of the MS program was "not like what real college students do." In addition to his opinion about the time constraints of the program, Matt expressed his desire for inclusive educational experiences.

School drives me insane... I want to take [degree-track] classes but everyone tells me I'm not there. Maybe I can take those classes when I'm a senior, but I want to take them now... I want to learn what I really want to learn... It's fun to walk around campus, to know people and to see them. But it's hard to meet people because in [MS] you don't meet regular people... I don't feel like most people feel. I don't want to tell people I'm just learning life stuff. If you can live by yourself for two or three months, you should be able to go to classes.

As Matt disclosed his feelings to me, I immediately envisioned him as powerless within MS. His attempts to rebel by not going to class were punished with academic probation. According to Matt, he was not allowed to take classes alongside students who did not have IDD. It appeared that Matt lacked control over his engagement in college

occupations, despite MS's mission to instill self-determination in its students. However, a meeting with MS's academic director showed me that Matt's self-determination may actually have been more effective than he knew. The academic director told me that they were making changes to the curriculum based on student feedback, and described MS's new academic program that would link the MS courses with degree-track courses in the university. The program, named Crosswalk, would allow MS students to fulfill program requirements by taking university courses outside of MS. For example, a sophomore-level class in the Special Education department, People with Disabilities in American Society, would meet the MS requirement for advocacy credits. Crosswalk was to be implemented in the following academic year, when Matt would be a sophomore, so it was possible that he would have the chance to engage in more-inclusive educational experiences.

Matt's example suggests that the MS program and the students might have had different interpretations of self-determination. Taking classes with degree-track students would have given him a sense of purpose as a college student, but he felt that the MS administration stifled his efforts to act upon his world. Still, the fact that Matt's expression of his desires to take classes with degree-track students influenced curriculum development at the administrative level indicates that the program was acknowledging Matt's input and thus supporting his self-determination.

Student-life support (SLS). As described above, student-life support staff (SLS) were degree-seeking undergraduate students at the university who worked with the freshmen and sophomores outside of class hours to facilitate their transition to college life. Students referred to SLS as something they "had," similar to a class or an

appointment. The following excerpt from my fieldnotes illustrates how MS students referred to SLS.

I visited Allison one weekend day for a scheduled observation. I knew she had SLS that day so I planned to observe their activities. As soon as I arrive, Allison's neighbor, Jessica, calls her. Within a few moments, Jessica shows up at Allison's apartment. "Who do you have today?" Jessica asks Allison. Allison tells her who her SLS students are today. She has SLS from noon to four o'clock, and another SLS from four o'clock to eight o'clock. Jessica has the same schedule with her SLS. "Who does your roommate have?" Jessica asks Allison. "She's off today," Allison responds.

SLS became a common aspect of the freshmen's and sophomores' experience. Some students expressed fondness for their SLS students, whereas others wished they had less time with SLS. One freshman, Kirk, reported that he did not like have SLS on Saturdays because those were his days to "kick back and relax." He expressed concern about becoming too dependent on SLS, especially for weekend activities. Still, Kirk stated that he liked having SLS on weekdays because SLS helped him with his homework.

Conclusion

This chapter has provided a detailed examination of MS through programmatic practices, the situated nature of the occupational experience, and the theoretical lens of figured worlds. Postsecondary education for students with IDD has been suggested as a figured world, and indeed, these students with IDD were living that figured world

through MS. An introduction to the discourse of MS was provided to supply further insight into how MS is a local space of practice for the figured world of postsecondary education for students with IDD.

Because MS is but one space of practice that lives within the figured world of postsecondary education for students with IDD, I will not generalize the practices described in this chapter to all other postsecondary programs, or spaces of practice, that are simultaneously enacting the same figured world. Instead, I emphasize that the practices described in this chapter are my interpretations of how MS relates to the figured world of postsecondary education for students with IDD. The MS students' engagement with these practices fostered their identities as members—more specifically, students—of the larger figured world.

Chapter 7

Stories of Inclusive (and Exclusive) Support

“20/20”

It is a chilly Monday evening in the middle of November, around five o'clock. Annie, Tory, and their friend, Valerie, each have Student Life Support (SLS) today.²⁰ Tory and Valerie have just arrived home from class and have headed straight to their apartment complex's clubhouse to meet their SLS. They are early since their SLS students are scheduled for five-thirty. Annie's SLS is scheduled for five o'clock but Annie is still on her way home from class. Tory and I go inside the clubhouse to wait because it is chilly outside. Valerie stays outside with Annie's SLS to await Annie and the two remaining SLS students. “We're going to the mall today,” Tory tells me while we wait. “We're going to take the bus to get there.”

Annie and one of the SLS students arrive around five-thirty. The remaining SLS still has not arrived. Meanwhile, Annie, Tory, Valerie, one SLS, and I go to Tory's apartment to drop off their school items. The other SLS stays to wait for her friend, who is the remaining SLS. She has arrived by the time we return to the clubhouse, so now all three Making Strides (MS) students and all three SLS students are accounted for. Brad, an MS teacher who coordinates the SLS students, has also arrived while we were at Tory's apartment.

“What are your plans for today?” Brad asks Annie, Tory, and Valerie. “We are going to the mall,” Tory says determinedly. Her pride is quickly overcome when one SLS

asks if they have figured out how to take the bus to the mall. Annie, Tory, and Valerie have not planned out the schedule, so the SLS suggests that they exercise at the student recreation center today instead. Brad agrees with this new plan. “You can go work out at the rec center tonight,” he says, “and then you can plan out the bus routes afterward so you can go to the mall another time.”

“I don’t want to work out,” Annie says, but Brad encourages Annie to go. He reminds her that exercising is part of her student life plan. “I work out in the mornings,” Annie retorts. “My mom knows that.” Brad says he does not believe her—in all honesty, I question her statement too. I have observed Annie many times in the mornings, but I have yet to see her work out during those times. “I want to go to the mall,” Annie says. I get nervous about how this night will turn out; Annie seems to be acting defiantly in the eyes of her MS teacher/SLS coordinator and SLS. Her posture and intonation clearly communicate that she is getting angry.

“This is part of PAST,” Brad reminds Annie, Tory, and Valerie. PAST is a decision-making strategy that the MS students learn as freshmen. It stands for Preference, Affordability, Safety, and Transportation; these are the areas to consider when making plans. “You have not thought through the T—you guys are sophomores!” Brad tells them in an exaggerated tone of disbelief that insinuates the importance of the PAST strategy. “Well, you need to come to a consensus. Majority rules,” he adds.

The decision is to go to the recreation center, although Annie makes it known that she does not support this plan. Still, she goes home to change out of her school clothes and into her workout attire. Annie returns, visibly upset and aggravated. “I’m not in a good mood right now,” she tells me. “I don’t like when people rush me.” She rolls her

eyes at her SLS as if telling me that her SLS rushed her to get ready for the gym. As we walk to the recreation center, Annie trails behind. The walk takes about twenty minutes even though we are only about a half-mile away. It is dark as we navigate the broken sidewalks. Annie's SLS tries to hurry her up. We barely make it through the crosswalk when the traffic signal turns. "You need to hurry up when you're crossing the street," Annie's SLS instructs her.

At the gym, the SLS students direct Annie, Tory, and Valerie to the indoor track. They point them in the direction to walk and show them the lanes to stay in. I stand by the water fountain to observe because I am not wearing appropriate attire. The SLS sit just outside the track area, talking to one another and texting on their cellular phones.

Annie, Tory, and Valerie begin walking and talking as a group, but they gradually separate into a quiet, linear formation. I "high-five" them as they lap each time. One SLS walks into the track area once in a while to briefly check on the MS students. After the fourth lap, Annie, Tory, and Valerie tell the SLS students that they have to use the bathroom. They are granted permission from one SLS to go. The SLS students continue to chat and use their cellular phones while the MS students are in the bathroom. They grow impatient with waiting for the MS students to return, so one SLS goes to check on them. She returns with a look of disbelief. "They were just sitting on the bathroom counter and talking," she tells the other SLS. "I told them they needed to come out." Sure enough, Annie, Tory, and Valerie return about a minute later. "You are done with the track," one SLS says. "Now you'll use the treadmills until Yogalates starts at seven." "I love Yogalates!" Tory exclaims. Annie and Valerie simply go along with this plan; Annie

ignores the SLS but is quietly following the group. She is still visibly upset as she keeps her arms crossed and rolls her eyes.

We go downstairs and find three treadmills together. The SLS students assign a machine to each MS student. The SLS students set the speed and incline of each treadmill before sitting down against the wall behind them. “I’m not even going to try with her,” I hear one of the SLS say, referring to Annie. Another SLS validates that Annie is being defiant. The third SLS gets up and walks over to Annie to tell her that “it is not nice to ignore SLS.” As if she’s had enough of this treatment, Annie yells back to the SLS, telling them why she is upset. But before she can justify her feelings, one SLS yells back, “We will talk about this later when we’re not in a public place.”

Annie continues on the treadmill, intermittently stepping on the static side rails to use her phone. Annie stops and goes, stops and goes. She shows her phone to Tory and they laugh together; I cannot see what is on the phone so I am unsure of what they are laughing about. Soon I am able to tell that Annie is watching music videos on her phone. She holds the phone to her ear, listening to the music while she walks. Again, her SLS says she’s not going to bother with Annie today.

One SLS gives a five-minute warning: Yogalates will start at seven o’clock. Three minutes later, a two-minute warning is given. Annie, Tory, and Valerie are told that they will get off the treadmills, get water, and then go to class. After two minutes, the SLS students stop the treadmills for each of their MS students.

“I don’t want to go Yogalates,” Annie tells the group. “I like 20/20 better.” The one SLS who is not frustrated with Annie asks her if she has ever done Yogalates before. “No. I want to do 20/20,” Annie responds. The SLS tells her that 20/20 isn’t tonight, but

this class will be less cardio so it will likely be easier. There are many university students heading toward the group exercise classroom. Even the SLS students will participate in the class. As we get closer to the classroom, the SLS realizes she was mistaken—the class beginning at seven is actually 20/20.

I breathe a sigh of relief. Will this realization be a turning point for Annie? Might this evening be salvageable? I look over at Annie—she does not seem excited. They head into the classroom and I leave them to 20/20.

Discussion

I chose this story because it illustrates how inclusive supports can actually be exclusive. What was structured to be a peer relationship between Annie and her SLS was more like that of a boss and a worker. The social divide separating MS student from SLS was painfully evident in the way that the SLS spoke to and directed the MS students. Furthermore, this situation suggested a contradiction of the MS program's value of self-determination. Taught to be self-determined in class, Annie's self-determination was thwarted in practice. This discussion explores the practice of inclusive supports as it was observed in this research. The benefits of inclusion are supported and, at the same time, questioned.

Support as Hierarchical or Shared Experiences

The MS program offered students with intellectual and developmental disabilities (IDD) age-appropriate experiences in an environment with their peers with and without disabilities. To facilitate the transition to this new environment, MS offered student-life support packages to freshmen and sophomores. According to program administrators, student-life supports (SLS) were college students who guided the underclassmen in social

connectivity on campus. The point of having college students serve in the SLS roles, as opposed to other support positions in the program that require a college degree, was to construct peer relationships that were natural: SLS and MS students were close in age and SLS were students who were navigating their undergraduate careers at the same time as the MS students. However, as illustrated in the story of Annie and the gym, the concept of peer support was often challenged in my observations. I more frequently observed a hierarchy than shared experiences. An implicit power dynamic seemed to override friendships between SLS and MS students.

I draw on another example from my fieldnotes to further support this imbalance. The following excerpt is from an after-school observation of Tory, Annie, and Annie's roommate, Jessica (an MS freshman). In this example, the three students are deciding how to spend their evening. As they discuss, it becomes evident that the SLS students have their own plans for the MS students.

The SLS students are talking about how awesome Zumba is and how they should go today. Jessica says she is going to go to the basketball game with her peer companion, a degree-track student volunteering with a university organization that supports inclusive community participation. Jessica's SLS says Jessica needs to do Zumba instead. The SLS has Jessica call her peer companion, and then takes the phone to cancel Jessica's plans for the basketball game... Upset after the phone call, Jessica laments that she wants to go to the game. Her SLS reiterates that Jessica has to work out. "Do you understand the confusion?" Jessica's SLS asks her. "This

is my job. You have goals to work on. They [the peer companions] just want to have fun with you.” [...] Meanwhile, the peer companion has called MS’s student life director. The student life director calls Jessica’s SLS and tells her that Jessica is going to the basketball game. The SLS, visibly agitated, calls the peer companion back and asks that they provide a schedule for their visits since “it is conflicting with Jessica’s goals.”

I am troubled by the apparent suppression of both Annie and Jessica’s self-determination in these examples. The paradox of self-determination introduced in Chapter 6 is echoed in these examples of Annie’s and Jessica’s expressions of what they did or did not want to do being overridden by their SLS. How can individuals learn the value of standing up for themselves when they are disparaged for trying? The sequestrations of self-determination by SLS inherently positions the SLS students as the MS students’ superiors, which further enforces hierarchy over shared experiences with peers.

Perhaps the hierarchy noted in these examples was unintentionally created by the MS program. Because the MS program pays SLS students an hourly wage, I question how the monetary incentive contributes to the power differential between SLS and MS students. After all, SLS is a job; in order to be successful at that job, and therefore to maintain it as a source of income, the SLS may steer the MS students’ activities in the directions of established goals. Lennox Terrion and Leonard (2010) analyzed the motivation of paid and unpaid peer mentors in higher education and found that paid as well as unpaid mentors were motivated by self-oriented reasons (e.g., fulfilling personal

needs) but that their primary motivations for being peer mentors varied. For example, paid peer mentors were motivated to help others, whereas unpaid peer mentors were motivated by fulfilling social needs. I infer from these findings that these paid mentors saw themselves as external forces acting upon their mentees' situations, while unpaid peer mentors saw themselves as acting with their mentees' situations.

I did not observe this apparent power differential with unpaid supports in the MS students' elective courses. For example, when Tory and Annie took a Therapeutic Recreation elective during the second semester of their sophomore year, their class participation was facilitated by undergraduate degree-track students who were volunteering as tutors. When I met Tory's tutor for the first time, she told me, "This is my favorite class, probably ever. I never thought about working with underserved populations before." The tutor's statement showed that her experience with Tory was mutually beneficial. Despite the social divide between them, both parties learned from one another. The tutor achieved more from the experience than a grade in the course; she gained a new perspective about her community.

Humphry's (2005) model of processes transforming occupations (PTO) can be employed to analyze the process of inclusive support when a differential in experience exists. PTO describes the development of occupation as multifaceted and synergistic and as influenced by the construction of occupational opportunities, social transactions, and self-organization of processes. One of the factors that Humphry identified as contributing to the development of occupation is social transactions. She emphasized the interpersonal nature of occupation by explaining how participating in occupations with others contributes to both the occupation's development and its meaningfulness for those

engaging in it. Humphry proposed that skilled partners facilitate occupational development of less-skilled partners through a process similar to scaffolding. For example, interactions Tory's Therapeutic Recreation tutor served as the skilled partner and Tory as the less-skilled partner. The tutor showed Tory how to engage in class occupations by instructing her, modeling for her, and helping her to understand the meanings of her experiences. The tutor was essentially Tory's occupational guide who showed her how to appropriately engage in course practices. Humphry explained that interaction with a skilled partner allows the less-experienced participant to develop occupational experience; such interactions create "a new sense of the *how*, *with what*, and *why*" (p. 41). I expand upon Humphry's statement by arguing that the skilled partner's performance and meaning are also enhanced by virtue of the shared experience. The above quote from Tory's tutor supports this claim.

This process of guiding the development of occupation occurred during the SLS experiences, but the outcomes of the process differed from the outcomes of experiences with the tutors because of the motivational factors that were transacting with the situation. I presumed that the "why" was institutionally influenced in the SLS-MS student situations because the SLS-MS relationship was constructed in the institutional realm of employment. SLS and MS students engaged in activities that were structured to achieve goals, but the "how" and "with what" aspects of the occupational situation were different when the MS students worked with SLS as opposed to peer tutors. With SLS, the "how" was dominated by the SLS students and the "with what" was the toolbox of skills taught by the MS program. In short, the social transactions between the SLS and MS students went beyond the individual students because they were steered by the MS program.

The Complexity of Inclusion

Power differentials aside, all of these examples show support for inclusive experiences. The SLS students theoretically provided opportunities for inclusive campus and community activities, whereas enrollment in elective courses offered MS and degree-track students inclusive educational opportunities. Dolyniuk et al. (2002) studied inclusive educational experiences of high school students in a three-week postsecondary education experience; similarly to Tory's experience in her elective in therapeutic recreation, their participants were mentored by fellow undergraduates. The authors concluded that developmentally appropriate education offers social equality for people with and without disabilities, as student mentors reported greater awareness about abilities of people with special needs as well as improved outlooks on inclusive experiences. Their study supports the benefits of implementing inclusive experiences in education.

The concept of inclusion must be also considered from a socio-cultural standpoint, despite the assumed benefit of its implementation. By advocating for inclusion, segregation (commonly regarded as the opposite of inclusion) has been ascribed a strongly negative connotation in education (see Uditsky & Hughson, 2012). My data from the sophomore class, however, did not demonstrate that segregation was necessarily detrimental. Compared to the MS freshmen, juniors, and seniors, the MS sophomores maintained a particularly tight peer group that did not give the impression of lacking in social experiences, despite spending much of their social and academic time with one another. I wondered if this cohesion is so different from theater majors spending their leisure time together. Perhaps it is not necessarily negative if common interests,

bonds, and ways of thinking and doing sometimes outweigh diversity. In fact, it might even have been easier for the sophomores to relate to one another as people with IDD than to try to relate to people without IDD.

As described in Chapter 2, Bagatell (2007) found similar results in her study of Ben, a young man with Asperger's. Ben preferred to participate in the "Aspie" world because engaging in the "Neurotypical" world required him to attempt the difficult task of fitting in with people without Asperger's. This is not to say that the MS students devalued their interactions with degree-track peers, nor is it an argument against inclusion. In fact, many of the MS students highly regarded that aspect of the program, as I had anticipated based on previous studies by Hamill (2003) and Redd (2004). Instead, this discussion draws attention to inclusion as socially constructed while questioning if the value placed on inclusion by disability advocates may be ethnocentric. After all, Annie's and Jessica's experiences with their SLS students, while theoretically beneficial because of their inclusive nature, were in reality anything but positive.

These stories illustrate that inclusion must be considered as more than simply collecting people of different abilities into the same place to do the same activities: the outcomes of inclusion must also be considered. Kids Together, Inc., a grassroots nonprofit organization that advocates for inclusive communities, has defined inclusion in terms that support this argument:

Inclusion is part of a much larger picture than just placement in the regular class within school. It is being included in life and participating using one's abilities in day to day activities as a member of the community... It is being a part of what everyone

else is, and being welcomed and embraced as a member who belongs. (2010)

The chance to interact with people outside of one's typical community offers opportunities for new experiences when both the skilled and the less-skilled participants are open to shared experiences (as was not apparently the case with Annie and Tory and their SLS students). The following excerpt from my fieldnotes describes an observation of Sean and his SLS, when Sean's SLS invited Sean to audition for his fraternity's talent show.

At 7:05, Sean's SLS suggests that they take a walk on campus to get out of the house, or Sean can audition for his fraternity's talent show. Sean gets very excited about the audition and chooses that option. "You didn't tell me about that!" Sean's SLS reminds him that he cannot get him an "automatic in" just because he is in the fraternity, but Sean can try out like everyone else. "Maybe someone will see you and like your style," Sean's SLS says. "Do you have something ready?" Sean replies, "Yeah, I freestyle!" He puts a CD into the DVD player and starts it, practicing a few songs first. It is 7:15 and the audition started at 7. Sean's SLS cues him to move quickly so they can make it. He calls his fraternity brother. "I'm going to bring my dude to audition," he tells the fraternity brother.

We walk to campus for the audition...When we get close, Sean looks nervous. He says he's never performed in front of people on

campus before. “Even if I don’t make it, I’m still a star,” he says.

We go into the room and there are two fraternity brothers waiting for us. A few others have auditioned but it’s a small turnout. We take our seats while Sean prepares his CD and then raps. At the end, one of the fraternity brothers says they will take his contact info and will let him know about the show.

This encounter exemplifies the peer relationships that the MS program aimed to foster through the SLS program. It is unlikely that Sean would have auditioned for the fraternity’s talent show without his SLS, as Sean had been unaware of the opportunity until their conversation. Sean enjoyed the prospect of fraternity life. “I’ve hung out with a fraternity before,” he once told me. “We went out to some clubs. I’d like to start my own fraternity.” Through this experience, Sean’s SLS became his connection to a fraternity on campus. Even more commendable was that Sean’s SLS went beyond exposing Sean to a campus activity and group by inviting Sean to share an aspect of his personal world.

Conclusion

This chapter presented stories of MS students interacting with peer supports without disabilities. It drew specific attention to the inconsistencies in inclusive support that I noted in my observations. As an example it presented the stories of Annie and Jessica, who experienced hierarchical relationships and diminished self-determination with their student supports. It illustrated positive experiences of peer support as well, for example Tory’s Therapeutic Recreation tutor and the story of Sean auditioning for the fraternity talent show with his SLS. Through these discrepancies, the complexity of inclusion was exemplified and discussed.

Chapter 8

Stories of Being a College Student

“Swag”

I get to Sean’s apartment around 5:15 after Sean and his roommate, Jason, have returned from class. Jason welcomes me into their home. He is making microwave popcorn. “We’re having a party tonight at nine o’clock,” Sean tells me. “Would you like to come?” I have to return home after the observation so I regretfully decline the invitation. Sean hands me a flyer anyway. “It’s a Sports Swag party,” he says. “Are you allowed to have parties here?” I ask, confounded by Sean’s openness about hosting one. I am remembering my own experience as a college student; parties in student housing were kept “under the radar” for fear of being disrupted by housing staff. “Of course,” Sean responds. “It’s what college students do.”

To prepare for the party, Sean says he will hand out flyers with his student-life support (SLS) around the housing complex. He goes into Jason’s room to discuss the plan for the evening. “How long will the party last?” Jason asks. “At least three hours,” Sean answers. Sean volunteers to make more popcorn and to hang the decorations. Jason seems nervous about the event. He asks how many people will be there and who the guests will be. He tells Sean that he does not want to do anything, except vacuum, to help prepare. “It will only be about eight of our friends,” Sean assures him.

Sean’s flyer boasts the party’s sports swag theme at the top. There are two of the same pictures of a sports magazine cover, one next to the other. The next line looks like

an emblem from a business called SWAG SPORTS. Next to the emblem are two more pictures—a rap star spinning a basketball and a different rap artist’s professional album picture (Sean is a rap aficionado). The description of the party reads, “Come have a blast and swag it out in your favorite sports gear / make sure to bring a sweat dish or some abdurbs for the party / there will also be popcorn and candy at the party.”

There is a knock at the door and Jason answers it. Brad, the instructor for MS’s Dimensions of Campus and Community Living course, walks in. He is also one of the SLS coordinators for Making Strides (MS), so it is common for him to check in on the freshmen and sophomores in the evenings. He has brought Sean’s SLS with him. This SLS is new to the program; he is starting this evening. Jason and Sean tell Brad about their party. I show them the flyer. “There is no time or address on the flyer,” Brad notes. Sean says he will tell people that information when he gives them the flyer. “We are having it after SLS hours because we’ve got to learn how to be without them and live independently,” Sean explains.

“This is for a Dimensions assignment,” Brad explains to me. “The assignment was to host a few people to watch a sporting event or something similar.” Brad reminds Sean and Jason to include what each of them did to prepare for the party when they write their reflection of the event. Brad sets up the new SLS (how to write Sean’s progress notes), and then he leaves. It is now Sean, Jason, Sean’s SLS, and me in the apartment.

“There’s a lot to do before the party,” Sean realizes. “I have to clean, decorate and hand out flyers. I don’t want people to come too early.” Sean instructs Jason to vacuum now. As he is vacuuming, Jason’s phone rings—his mother is calling. I hear him tell his mother about the party and they seem to be discussing it. “Just about eight people, Mom,”

Jason says. They talk for a few more moments before Jason hangs up the phone. “Sean, my mother says that only people in MS can come to the party.” Sean rolls his eyes.

“Don’t listen to that,” he says. “We’re in college now and you can’t always be listening to your mother.” Sean offers a compromise. “How about this. You can invite MS people, but I’m going to invite the people I planned to invite—friends from my ministry and from home.” “I’ll have to talk to my mother,” Jason retorts. He dials her number and hands the phone to Sean. “You deal with her, she’s your mom!” Sean exclaims. “Don’t be a mama’s boy,” he adds.

Jason takes the phone call in his room while Sean, the SLS and I stay in the kitchen area. “We’re all university students,” Sean says. “Everyone gets included, that’s the point of inclusion. Jason is in college now and he doesn’t have to listen to his mom anymore. I’m just trying to help him be confident. University students are university students, just like MS students are. We are all university students; we include everyone.” He continues, “I’m showing Jason how to be a self-advocate because people with disabilities tend to listen to what their parents tell them. That’s why people with disabilities have the reputation they have. I’m in college; I can do what I want to do.”

Jason rejoins us after his phone call. “She says you can invite other people, but only if they are positive and only a few of them,” he instructs Sean. Sean replies, “The people I’m inviting are positive. They are from the ministry and they don’t drink. You’re going to get a reputation, Jason. There shouldn’t be segregation. That’s the problem right there.”

Another knock at the door—this time it is Sean and Jason’s classmate, Max, and Max’s SLS. Sean welcomes them in. Max is wearing a basketball jersey for the party.

“There was no time or address on the flyer, Sean,” Max’s SLS says. “Do you want us to leave and come back for the party or should we stay?” Sean invites them to stay while they prepare, adding that the party will start at nine o’clock after the SLS leaves. Since the start time is notably missing from the flyer, Sean takes the flyers into his room and handwrites the time on each of them. He yells back to Jason to get ready to hand out flyers.

When Sean and Jason reconvene, Sean instructs Jason to put fresh clothes on. “Our reputation is important,” Sean explains. “We need to impress the ladies or else they won’t come. Get a hat.” While Jason retrieves a hat, Sean demonstrates the level of attire he expects by showing us the scarf he is wearing. “It’s a swag rag,” he tells us. Jason returns with his hat facing backwards. “Put it forwards and put your hood over it,” Sean advises. “My mom said to wear it backwards,” Jason responds. “Fine, that looks better anyway,” Sean concedes.

I go with Sean, Jason and Sean’s SLS to pass out flyers. We stop by the apartments of people Sean knows from home, as well as other MS students. We check the clubhouse for additional friends before heading back to Sean and Jason’s apartment.

“This is the first party I’ve ever thrown, so I need some help with decorations and setting it up,” Sean tells his SLS and me. He adds, “I have the confidence to throw a party now.” We all help hang decorations (sports shots) and I advise Sean to clean the bathroom so people can use it.

At 7:30, Max and his SLS get up to leave. The SLS explains that she was Max’s ride here and she gets off work soon. Since Max lives on the other side of campus, staying at the party would require a very long walk home in the dark. The SLS offers

Max the choice to stay; he ultimately decides to go with her. Since I have to leave as well, I ask Sean to call me tomorrow to tell me about the party. I later hear from Sean that the party went as well as he expected. “It was awesome,” he told me. “We had some lady friends I know from high school come watch the game with us.”

Discussion

I chose this story to illustrate being a college student because it illuminates the undeniable relationship of occupation and identity. By hosting a party, Sean enacted the identities of college student and independent young adult. On a larger scale, Sean’s party challenged the stereotypical expectations for people with intellectual and developmental disabilities (IDD). In essence, he enacted the overlapping identities of college student, independent young adult, and capable person with an IDD through the activity of hosting a party. The MS program’s influence on Sean’s occupations and identities must not be overlooked in this process, since this was an assignment for his Dimensions class. I will explore these themes of occupation and identity in the next sections of this chapter.

Doing Identity: The Dialectical Relationship of Identity and Occupation

Identity and occupation have a dialectical relationship in which the two constructs are tightly interwoven. Laliberte Rudman (2002) explained that while occupation influences identity, identity also influences occupation. But what is identity? Is it truly as individual as it is typically credited to be? Sean expressed being a college student and being independent, but he also referred to the “reputation” of people with disabilities (i.e., how they are perceived by others).

Laliberte Rudman (2002) deconstructed identity into two definitions. The first, *personal identity*, refers to “the arrangement of self-perceptions and self-evaluations that

are meaningful to a person” (p. 12), and the second, *social identity*, refers to “how a person is viewed by others” (p. 12).²¹ Using these definitions, Laliberte Rudman conducted a secondary analysis of three qualitative studies to explore how individuals express who they are through occupation. She concluded that people make occupational choices in line with their personal identity while simultaneously making occupational choices to project social identity. In essence, people “do” identity, a point that Laliberte Rudman expanded in 2010 with her co-author, occupational scientist Suzanne Huot. In Sean’s story, I interpret him “doing” identity through the sports swag party. Although the party was an assignment, Sean expressed that hosting parties is “what college students do” (this is an expression of Sean’s personal identity). Similarly, the party projected his college student identity to others in the university environment while showing them that people with disabilities can still do what they want to do (this is an expression of Sean’s social identity).

Changes in occupation and identity. The association of occupation and identity is further reinforced in literature on disability and chronic illness. Changes in occupations resulting from disability and illness have been shown to strongly impact the identities of individuals with impairments (Alsaker & Josephsson, 2003; Asaba & Jackson, 2011; Braveman, & Helfrich, 2001; Jakobsen, 2001; Magnus, 2001; Laliberte Rudman, 2002). These changes in individuals’ occupations and identities have been shown to further influence the occupations and identities of other people in their social network (e.g., caregivers), thus demonstrating the interpersonal nature of the identity-occupation relationship (Hasselkus & Murray, 2007; Laliberte Rudman; Segal, 2005).

Expanding beyond disease and disability, Huot and Laliberte Rudman (2010) explored how changes in occupation and identity unfold during the process of migration. The authors argued for place to be considered as an influential factor in the change process. They explained that interacting with unfamiliar people and facing foreign social norms, as when migrants move, necessitates new ways of doing occupations. This novel occupational engagement, in turn, gives rise to the development or reshaping of identities. The process of migration can be likened to the current study in the sense that the students were migrating to a new place—college—and thus experiencing changes in occupational engagement and identity formation. Sean's swag party illustrates this process. As part of the migration to college, Sean was learning new ways and norms of socializing with his college-student peers.

Constructing Opportunities for Occupation and Identity Development

I do not know if Sean would have thrown a party if the endeavor had not been prompted by a class assignment. This uncertainty led me to explore how MS constructed the students' experiences of occupation and identity. Humphry's (2005) model of processes transforming occupations (PTO) explains that communities contribute to the development of or transformations in occupations by creating opportunities for members' engagement in common cultural practices. One way that MS created opportunities for the MS students' engagement in common student practices was through the Dimensions of Campus and Community Living Course (Dimensions for short). Offered separately to MS freshmen and sophomores, Dimensions was structured to facilitate MS underclassmen's transition to college. It focused on five areas: campus, arts, sports, navigation, and nutrition. Students learned how to participate in their campus and local city communities

by completing community-based assignments. In addition to hosting a small gathering (as in Sean's story), assignments for this course included attending campus events for Welcome Week and Homecoming, utilizing the recreation center for fitness activities, creating a recipe box, going to the library, participating in student clubs, attending a university sporting event, learning about intramural sports on campus, visiting a cultural arts center, and riding the city bus to a store or bank. While the instructor's stated goal for this course was to involve students in their campus and city communities, the course also fostered freshmen and sophomores' student identity development through occupational engagement. The majority of the required campus activities were exclusive to university students, so their very involvement included them in a distinct population of college students. It was evident to me that being a college student was constructed through participation in these cultural practices. MS juniors and seniors continued participation in some of these cultural practices that had been instilled in them as freshmen and sophomores. For example, George, Benjamin, and Zachary frequented university sporting events on campus. Zachary went to the student recreation center for weightlifting classes and to play basketball with his friends. Chip could often be found reading in the university library on weekends.

Rules: The Practical Application of Occupation and Identity

Because Dimensions assignments were given as homework, the MS freshmen and sophomores completed the tasks after school and on weekends. These were also the times that the MS students worked with SLS (if a support plan was in place), so SLS typically facilitated the MS students' completion of Dimensions assignments. The role of SLS was more than an assistant, however: SLS were required to note the students' progress toward

specific skills associated with the Dimensions coursework. Associated skills for freshmen included “scheduling and planning for leisure activities,” “identifying interest and hobbies,” and “practicing good safety, hygiene, etiquette in varied community settings.” For sophomores, associated skills included “structuring free time to be managed independently,” “application of scheduling and planning skills,” and “regular involvement in campus and community organizations and volunteerism.” The MS program constructed these community-involvement skills as critical to the student experience by emphasizing them as areas for support.

“Doing” identity has been discussed in previous sections but I expand the conversation here to give further insight into the related processes of doing and identity formation. Dickie (2003) posited that implicit rules guide identity development. In her study of craft workers, Dickie found that the participants followed specific rules that allowed them to achieve the worker identity. The rules were task-based (e.g., acquiring supplies and displaying work in a specific manner) and were summarized by the various contexts in which they were relevant. Dickie explained that “by following these rules, individuals enacted the identity of being a worker in their particular craft” (p. 254). Some of the rules for achieving the student identity can be inferred to be the task-based applications for the skills associated with Dimensions (listed above). By following these rules, the students were doing the student identity. For example, students followed the rule of “regular involvement in campus and community organizations” by going to the student recreation center. The MS program demonstrated the significance of this rule by posting a schedule of fitness classes on the informational bulletin board near its offices on campus. For their part, SLS encouraged freshman and sophomore MS students to follow

this rule by bringing them to the student recreation center to exercise. Going to the campus gym enabled the participants to be in student-only environments and to engage in occupations with other college students, thereby contributing to the development of the student identity.

The MS program also set rules for achieving the student identity by establishing a grading scheme for all of its group classes. Course grades for group classes were figured by factors of attendance, participation and preparation, quizzes, projects, midterms, finals, and homework. The structure of the grading model inherently communicated that students had to attend, participate in, and be prepared for class; in addition, they had to perform well on quizzes, projects, midterms, finals, and homework in order to be students in the MS program. Students internalized meeting these criteria as aspects of the student identity. For example, when I asked Zachary what a college student was, he responded, “I think a college student is, they go to every single class...which I do not like...” Allison responded to the same question with a similar answer: “[College students] go to school.... Study.”

The grading criteria were also a part of the MS culture’s discourse. I observed instructors talking about the grading criteria with students throughout the school year, and witnessed students discussing it with one another, as the following entry from my fieldnotes illustrates:

Chip tells me they had a quiz last class. He says their classmate missed it.

“We were lucky we were here,” Chip says. “I tried to get him to come but he wouldn’t,” Benjamin says. “He was being stubborn about it. I told him it would affect his grade in class but he didn’t listen.”

The MS program's emphasis on these grading criteria showed up frequently in observations and interviews throughout the year, in and outside of class, thereby demonstrating the inherent impact that grading criteria had upon the construction of student occupations and identities.

Breaking the rules. The MS program's academic rules could be difficult to follow because the attendance and participation criteria in the grading scheme required students to attend all classes. For MS freshmen and sophomores, this meant attendance in classes that equaled 21 credit hours of group and individual meetings per semester (internship and volunteer hours replaced some of the group classes as MS students became upperclassmen). In addition to being full, the MS students' schedules were rigid. Unlike college students without disabilities, who generally pick their own schedules, the MS program arranges its students' schedules for them. Group class times were inflexible, and students were expected to enroll in the MS classes whenever they were scheduled. Electives were granted a bit more flexibility, but their timing had to fit with the MS program's required courses.

Some of the participants in this study had difficulty meeting the intense curricular requirements that were in place at the time, most notably because there were simply too many classes. Matt, a freshman, disagreed with the MS scheduling system. He felt that classes were too long and inhibited his ability feel like a "real" college student. "It's not like what real college students do," he reported in his initial interview in answer to a question about his experience in MS. He added that college students do not take classes from nine o'clock in the morning to five o'clock in the evening, especially classes about social skills and cooking. Matt also lamented that he could no longer play frisbee with the

people he had met on campus during his first semester, because he had too many classes. His reflection illustrated how time commitments for academic responsibilities interfered with social and leisure occupations for some MS students. During this initial meeting, Matt disclosed that he was on academic probation. “I missed a lot of classes last semester,” he admitted. “I didn’t see the point in going.” He reported that he was going more frequently in the second semester, mostly to be around people his age.

Laliberte Rudman (2002) suggested that occupation, while supporting identity formation, may also be a barrier to identity development. This barrier effect occurs when an individual is unable to do something and is therefore unable to develop a valued identity. Matt, for example, missed taking classes with non-IDD students on campus; according to his account, his academic responsibilities impeded his identity as a college student. Matt struggled with a repetitive cycle of barriers: he did not like the amount of classes he was supposed to attend, or the content of those classes, because he felt they were not what “real” college students were supposed to do; as a result, he did not feel like a college student. Yet when Matt stopped going to class, he further impeded his college student identity development. He decided to go again when he realized that classes allowed him opportunities to socialize with his same-age peers (i.e., that going to class did have a feature that that he could use to further his college student identity development).

Proximity to campus also created a barrier to class attendance and participation that contributed to rule-breaking. George, a junior, lived farther from campus than any other study participant; unlike the majority of his peers, his apartment was not located within walking distance to campus. George constantly struggled with missing morning

classes due to his difficulty with waking up on time. At the beginning of the second semester, one instructor told her junior class to expect last semester's report cards soon. She looked disparagingly at George, who happened to be in class that day, as she added, "Some people will have lower grades because of poor attendance."

When possible, the MS staff made concessions to its schedules for home visits and other adjustments. In the second semester of George's junior year, the MS instructors decided that he could be more successful with attending and participating in his internships rather than continuing to attend group classes on campus. "Juniors in college typically get to pick their classes from a flexible selection," one instructor explained. "So we're counting his internships toward his credits for graduation." This change in George's schedule resulted in greater attendance and participation; essentially, the program made the rules easier for George to follow so that he could be more successful. These concessions, which were akin to the accommodations that I made for Kendra in the pilot study, allowed students to meet curricular requirements through altered methods without lowering program standards.

Even with concessions and support, however, whether to follow the rules or not was ultimately the students' choice. Zachary, like George, struggled with going to class. He was considered a senior for this study because he began the program with that group of students, but technically he was a junior because he had missed so much class time. "I did miss class on Wednesday last week," Zachary admitted to me in an interview. He continued:

I'm trying to get back on that—I'm trying to get back onto the—this thing called enrollment. I keep going to class every day and sometimes I do—

well, sometimes, actually no, sometimes I don't, but—but they try to find a way to get me back on track...trying to get me to go to class every day.

For Zachary, the consequence of breaking the rules meant that he would not graduate at the end of the current academic year because his parents and the MS program were requiring him to repeat the year. Zachary resented this imposition. In a joint interview with him and Claire, Zachary's girlfriend, he told me that he was angry he would not be graduating with Claire. "You should have gone to class," Claire said jokingly.

Conclusion

This chapter has explored the dialectical relationship of occupation and identity through discussion of the MS students' experiences of being college students. Stories were presented to demonstrate how the MS students developed their student identities through occupational engagement. At the same time, the stories also illustrated how the MS students developed their occupations through their identities. Occupations as well as identities were constructed both for and by the students as they engaged in college experiences. Specifically, findings from this study highlight program administration and social interactions as key influences on occupational engagement and identity development. I end this chapter with the declaration that identity—including personal identity—is inherently social. Despite the common perception of identity as belonging to an individual, this chapter evinces that identity is socially constructed and unfolding.

Chapter 9

Conclusion

Introduction

This chapter presents a final discussion of this dissertation research. It begins by addressing the main conclusions from the study, including the transactional nature of engagement in postsecondary education for students with intellectual and developmental disabilities (IDD) and the dialectical relationship of occupation and identity. The chapter then considers areas for further study, the contributions of this research to the discipline of occupational science and other fields, and the limitations of this research. It concludes with some of my personal reflections about this research experience.

The Transactional Nature of Engagement in Postsecondary Education for Students with IDD

My data confirmed that the students' engagement in postsecondary education was multifaceted and transactional as I noted various dynamic factors that came together to influence and situate the students' engagement. Among these factors were the MS administrative personnel, the MS support staff, and the MS students themselves. These factors transacted with one another, as well as with historical, institutional, and physical contextual factors, to shape the students' engagement. The coordination of these various factors embodied the transactional philosophy in practice.

Perhaps the most prominent transacting element was the MS program's construction of its students' engagement in postsecondary education. MS structured the MS students' curricular and extracurricular activities in order to allow them opportunities

to enact (live) the figured world of postsecondary education. MS staff guided the students to engage in novel occupations that reflected this figured world's values of self-determination and self-advocacy for college students with IDD. Unfortunately, this structure sometimes created a paradox of self-determination, for example when student-life supports (SLS) enforced MS undergraduates' participation in activities. The often-observed hierarchical relationships among the MS students and SLS had the power to negatively influence the MS students' occupational experiences if they did not agree with the plans that SLS had for them (see Annie's experiences in Chapter 7).

Occupation and Identity

As noted in Chapter 1, I chose to focus this study on the transitional period of postsecondary education because I anticipated plentiful opportunities to observe the dynamic relationship of occupation and identity in practice. My pilot study with Kendra also supported my perception of this period of transition as an opportune time to observe numerous facets of occupation and identity. As predicted, the transitional period of postsecondary education in this dissertation research provided a rich cultural landscape within which the students enacted the dynamic relationship between occupation and identity.

My data support Holland et al. (1998), Laliberte Rudman (2002), and Huot and Laliberte Rudman's (2010) explication of the relationship of occupation (or activity) and identity as dialectical. The students engaged in occupations that contributed to the development of their student identities (e.g., going to class, doing homework, participating in campus activities and events). Similarly, as college students they engaged

in specific occupations that reflected their student identity (e.g., sporting events and parties).

Areas for Further Study

Research has shown that exercising self-determination supports the successful postsecondary experiences of students with disabilities (Finn, Getzel, & McManus, 2008; Getzel & Thoma, 2008). Although it was not initially established as a guiding theme, self-determination emerged as a prominent aspect of the students' experiences as I conducted the study and reflected on the data. This study offers preliminary insight into how self-determination is communicated and experienced in MS. Additional exploration of the instruction about and implementation of self-determination, as well as the potential discrepancies among staff and MS students' interpretations of self-determination, would yield additional information about self-determination in the MS culture. Such information could be used to support the successful postsecondary education experiences of future MS students.

Another area for further study is the social relationships that MS students have with their paid and unpaid supports. This research would necessitate interviews with MS staff and MS students' non-IDD classmates, procedures that I did not implement in this study. Information from this type of research would allow deeper insight into the transactional nature of the MS students' occupational experiences, however, and findings could also be useful in addressing the issues of hierarchy that I noted in some of the relationships between MS students and their SLS.

Contribution to Occupational Science and Related Fields

This research contributes to occupational science by introducing a new area of occupational engagement for a population that has historically been blocked from such experiences (Grigal et al., 2012; Neubert, et al., 2001). Because people with IDD have traditionally been steered toward sheltered workshops and group homes after high school, little is known about how they experience engagement in postsecondary education. This study, which specifically explored how students with IDD engaged in a four-year, full-time college experience, has expanded upon my own pilot study in terms of both methodology and breadth. In addition, this study advances the discourse on identity and occupation in occupational science. The dialectical relationship of occupation and identity has been conceptualized in the occupational science literature (Asaba & Jackson, 2011; Braveman, & Helfrich, 2001; Christiansen, 2000; Dickie, 2003; Huot, & Laliberte Rudman, 2010; Laliberte Rudman, 2002; Phelan & Kinsella, 2009; Segal, 2005), but has yet to be explored in the population of college students with IDD. The participants' experiences in this study yielded extensive data that build upon the dialectical relationship of occupation and identity by illustrating how this relationship unfolds for college students with IDD during a transitional period.

The contributions of this study extend beyond the discipline of occupational science to higher education- and IDD-related fields. It supports the occupation-based study of students with IDD in postsecondary education by offering an ethnographic methodology that delves into the subjective experiences of the students as they engage in college occupations. Previous descriptions of postsecondary education for students with IDD have been limited to reviews of programmatic practices conducted through surveys

and evaluations of administrative personnel. Moreover, this study has practical implications for postsecondary education programs for students with IDD because its findings can be used to inform programmatic practices that appreciate the holistic, transactional nature of students' engagement.

Limitations

My methodology may have been a limiting factor in this research. Although the evolution from a multiple-case study to ethnography allowed for attention to cultural factors, my designations of primary and secondary participants might have deterred me from fully appreciating the culture as whole. I do not see this limitation to be significantly adverse, however, as I believe my cultural lens became more focused throughout the iterative processes of data collection and analysis.

My minimal interaction with students in electives and integrated courses is an additional limitation. It is possible that I paid so much attention to the students in the MS program that I overlooked the importance of the unpaid degree-track students who were also part of the MS students' experiences. Conducting secondary participant interviews would have given me further insight into how students without disabilities were part of the MS culture and the MS students' experiences.

A Personal Reflection

I have learned to embrace uncertainty through this dissertation process. What I thought I knew about qualitative research, occupation, and identity at the time of my proposal was immediately challenged as I entered the field. I learned to be flexible in my practices such that I knew how to find another participant if the scheduled participant was unavailable and could write my fieldnotes when I returned home rather than attaching

myself to a notebook during observations. Perhaps most important, I learned that identity and occupation were not as separate as I had initially theorized. I still refer to them as individual constructs, but only for lack of a better term (at least until “identipation” or “identitivity” become recognized nouns). I had to do this study in order to understand the true complexity of identity and occupation.

An additional aspect of uncertainty was the final product. I began writing this dissertation in the style of a traditional research paper, which means that I wrote chapters of findings followed by chapters of discussions, and produced many pages. Yet something did not feel right; I was not staying true to my participants and their experiences in my write-up. The current product is a result of discussions with members of my committee and family who, I am thankful to say, reminded me of the richness of my data. The ethnographic stories contained herein represent the participants, the participants’ experiences, and my experiences with them, in a way that I feel honors the participants. I started this experience with the intention to conduct and write a dissertation, but I am ending it with the additional intention to give back to the participants and the MS community out of gratitude for the information they gave me. I will share my insights with MS staff and students in the hope that I can contribute to the development of MS.

My purpose as a researcher has evolved during this process. One of my committee members suggested that I reflect on the difficulties I had to negotiate throughout the research process. I immediately thought about how I learned to manage challenging conversations with the participants, such as when we discussed complex, personal decisions. For example, fertility was an issue that three participants raised with me during

data collection. Each student reported having surgical procedures for sterility—decisions usually made by their parents but agreed upon by the students—yet they also expressed the desire to have kids at a later point in their lives. I was concerned that these young adults did not fully understand the life-altering procedures to which they had consented. Over the course of my interactions with these students, I learned to negotiate how I responded during conversations about sterility. I set personal boundaries as a researcher that allowed me to probe these situations without inserting my personal judgments.

This study impacted me on a personal level. I formed friendships with the participants that became more than the simple researcher-participants relationships I had expected. I felt joy for them when they passed a test; I felt sad for them when they were lonely; I wanted to fight for them when they felt ignored. I am grateful that these students shared their lives with me not just as a researcher, but as a friend.

A final word about postsecondary education. I began this study questioning how appropriate college could truly be for students with IDD. In retrospect, I realize that I was viewing postsecondary education from the same narrow lens that has propagated the higher education community. Over the course of this research, I found that the exclusivity of higher education is due to a sociocultural focus on deliverable knowledge as highly cerebral content restricted to the cognitively elite. This stance reinforces the bias of postsecondary education against students with IDD. Instead, we must focus on postsecondary education as a process not only of book learning, but also of social, cultural, and personal learning as well as a medium for identity development. In essence,

I feel that we limit the scope of knowledge by defining it. Only with this refreshed perspective of the learning process can we allow all students, regardless of ability, to participate and benefit from postsecondary education.

Notes

¹ See Appendix A for more detailed qualification of intellectual disability and developmental disability.

² The products of completion for students with special needs, including students with IDD, vary nationally. Some students leave with a certificate of attendance while others achieve a special-education diploma.

³ The NLTS2 definition of postsecondary education includes two-year or community colleges, vocational, business, and technical schools, and four-year colleges. Dual-enrollment programs are excluded from NLTS2 data

⁴ NLTS2 parsed disabilities into the following categories: Learning disability, Speech/language impairment, Emotional disturbance, Hearing impairment, Orthopedic impairment, Other health impairment, Autism, Traumatic brain injury, Multiple disabilities, and Deaf-blindness. Because an intellectual disability cannot be automatically inferred from any category (other than mental retardation), only the data from the mental retardation category will be used in this dissertation to describe people with intellectual disabilities.

⁵ Definition and example of accommodation as opposed to modification can be found in Appendix A.

⁶ The need to label identity as occupational is an argument that has not yet been resolved in the occupational science and occupational therapy communities. With identity understandably so dynamically linked to occupation, as presented in this review, I am not convinced of the necessity to qualify identity as occupational; therefore, I to use the term “identity” throughout this dissertation.

⁷ Kielfhofner (2002), Unruh (2002), and Unruh et al. (2002) all alluded to the potential disruption of occupation during health or life crises, and contended that these changes in occupation invariably impact occupational identity.

⁸ For further information on the political marginalization of people with disabilities, and to understand how current opportunities for people with disabilities have arisen from disability rights advocates, see Longmore, 2000; McCarthy, 2003; Scotch, 1989, 2000).

⁹ Kendra's faculty mentors at the CIDD said that she had a developmental disability but not an intellectual disability. The most recent testing of Kendra's intellectual functioning, which had been done more than 10 years prior, did not suggest an intelligence quotient that would meet the diagnosis of an intellectual disability. Since Kendra had not been formally diagnosed with an intellectual disability, I use the term developmental disability (DD) in her story.

¹⁰ This pilot study was submitted to the University of North Carolina's Institutional Review Board. It was deemed exempt.

¹¹ Kendra did not identify as a person with a DD. She seemed to refer to people with DD as if they were "others," foreign to her own profile. Rather, person with a DD seemed to be an identity attributed to Kendra by her peers and mentors. She did, however, speak of having a disability, without qualifying it as "developmental."

¹² Kendra used an electronic tablet to type her reflective journal entries. Due to her challenges with fine motor skills, her entries contain typographical errors. When the errors impeded my comprehension of the content, I consulted Kendra for clarification.

¹³ Kendra was already auditing the course. In fact, many of the graduate students were already auditing the course because they did not need the extra credit hours. It was not unusual for Kendra to do the same, especially since she was not a full-time degree-track student.

¹⁴ The U.S. Department of Education (2012) reported that 84.4% of full-time American college students were between these ages in 2010. That figure was projected to stay nearly the same in 2011, the year that this study was initiated.

¹⁵ Other students relocated to this university for the same logical reason. Some students expressed desire to attend the university that I attended because it was closer to their families' homes and they had friends there.

¹⁶ Matt and Benjamin were enrolled in the study during the second semester. I decided to enroll two more participants in order to collect additional data.

¹⁷ Per Bratun and Asaba's (2008) description, "Qi Gong is an ancient form of body and mind exercise, deeply rooted in Chinese culture and based on Taoist philosophical principles..." People practice Qi Gong individually or in groups.

¹⁸ Group homes are not without their disadvantages for health promotion. Residents of group homes may also eat unhealthily, but my discussion here points to the variation in restrictive supports for residents of group homes compared to those living independently. For example, Lewis et al. (2002) found that "individuals living independently were more than twice as likely as those in facilities to want to lose weight and more than twice as likely to need to lose weight, which most likely reflects greater (or less restricted) access to food, coupled with failure to exercise on a regular

basis. Those individuals with developmental disabilities living alone, or with family/friends, had the highest rates of obesity.” (p. 181)

¹⁹ Wehmeyer (2004) explained that the construct “self-determination” is ambiguous because of its complex historical roots and proposes causal agency theory as a replacement because it appreciates the assertion of control, purposeful action, and drive for change that the construct of self-determination implies in the disability literature. Although noticeable overlap exists among the implications of self-determination and agency, in this dissertation self-determination is used rather than agency because of its common use in the MS discourse.

²⁰ Student Life Support (SLS) is explained in detail in the experiential lexicon section of Chapter 6. As a reminder to the reader, SLS are degree-track students who are paid to facilitate the transitions of freshmen and sophomores to college. SLS was used to describe one paid support or as a collective (“Who is your SLS today?” “When is our SLS coming?”).

²¹ Sean used the word “reputation” multiple times, which implied that he was aware of how people perceived him and people with disabilities. I infer reputation to equate to social identity because both constructs reflect the perceptions of others.

Appendix A: Definitions

Accommodations and modifications are made to facilitate the learner's access to the curriculum. An *accommodation* changes the way material is communicated or work is completed in order to compensate for the disability, such as when a test is read orally to a student with a visual impairment. A *modification* is a change to the expectations for the students' performance as a result of the disability, such as when requirements for an assignment are made easier for the student with a disability. (National Dissemination Center for Children with Disabilities, 2010)

Developmental disability (DD). As defined in the The Developmental Disabilities Assistance and Bill of Rights Act (2000), *developmental disabilities* are similar to intellectual disabilities but diagnosing them does not involve quantifying intelligence. They are attributable to mental and/or physical impairments that develop in childhood or young adulthood. Developmental disabilities, like intellectual disabilities, are expressed as limitations in areas such as self-care, language, learning, mobility, and independent living.

Intellectual and developmental disabilities. Not all people with *developmental disabilities* (DD) qualify or identify as having an *intellectual disability* (ID). The target population for this dissertation represented people with developmental disabilities who had secondary intellectual disabilities. As such, the population of interest in this dissertation is referred to as people with intellectual and developmental disabilities (IDD). These disabilities may be used synonymously in the referenced literature.

Intellectual disability (ID). For the purposes of this study, the American Association of Intellectual and Developmental Disabilities' (AAIDD) definition of *intellectual disability*

is used. According to the AAIDD (2012), an intellectual disability is “a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills [that] originates before the age of 18.” The AAIDD characterized adaptive behavior as conceptual skills, social skills, and practical skills. These categories provide a comprehensive approach to understanding how individuals with intellectual disabilities participate in their daily lives. The AAIDD suggests that standardized behavioral assessments and intelligence quotient (IQ) tests may be used to determine intellectual ability; by its standards, an IQ of below 70–75 indicates an intellectual disability. This IQ score previously labeled people with a diagnosis of mental retardation; in this dissertation, intellectual disability is used in place of mental retardation to reflect current practice. Still, the AAIDD encourages professionals to consider physical, social, and cultural environmental influences on behavior; its own, function-based definition provides a holistic perspective of intellectual ability that does not necessitate standardized assessments. Therefore this definition is fitting for qualitative research, such as this dissertation, that does not quantify intellectual ability.

Postsecondary Education (PSE). *Postsecondary education* refers to continued structured learning beyond public or private high school (Think College, 2012). Postsecondary education occurs at vocational training programs, community colleges, and four-year universities. When students attend programs at community colleges and four-year universities, this period of learning may also be termed “college” or “higher education.”

Appendix B: MS Course Catalog

[Making Strides]©

Revised October 24, 2011

Reprinted with permission from Making Strides

All classes in ICS course of study in the University Catalog designated with CTP (Comprehensive Transition and Post Secondary Program). Courses organized by general topic areas.

PERSONAL WELL BEING ON T HE COLLEGE CAMPUS

CTP 101 Healthy Lifestyles

Introduction to methods for managing personal health including development of personal health record (PHR); elements of healthcare advocacy; physical abnd emotional wellness; management of risks to health. (Fall and Spring)

CTP 111 Adjusting to College Life

Introduction to university environment and campus life; personal safety in college; self-defense techniques; introduction to basic first aid; emergency preparedness (Fall and Spring)

CTP 141 Healthy College Life: An Overview

Guided review of ICS learning objectives related to personal well-being and community safety. (Summer)

CTP 161 Health and Personal Performance

Continued exploration of health, safety and wellness strategies necessary to be successful in collegiate environment. (Summer)

CTP 201 Healthy Lifestyles II

Pr. 101 or equivalent

Exploration of emotional health supports/resources on campus and in community; basic first aid; personal wellness strategies; advanced skills in managing medical conditions. (Fall and Spring)

CTP 211 Adjusting to College Life II

Pr. 111 or equivalent

Advanced exploration of disaster planning; crime prevention in university environment; recognition of household related dangers and response; prevention of dating violence; self-defense. (Fall and Spring)

CTP 221 Self-Realization: Making the Most of Personal Choices

Exploration of personal awareness and esteem building techniques; recognition of safe, responsible sexual behavior; recognition of personal choices that can impact health and/or safety; techniques for assertively communication personal choices (Fall and Spring)

CTP 241 Healthy College Life II: An Overview

Guided review of foundational ICS learning objectives related to personal well-being and community safety as highlighted in CTP 201/211. (Summer)

CTP 261 Health and Personal Performance II

Continued exploration of foundational health, safety and wellness strategies necessary to be successful in collegiate environment. (Summer)

CTP 341 Road to Personal Success I

Guided review of advanced ICS learning objectives related to personal well-being and community safety. (Summer)

CTP 361 Road to Personal Success II

Continued exploration of advanced health, safety and wellness strategies necessary to be successful in collegiate environment; focus on post-graduate preparation. (Summer)

NUTRITION**CTP 102 Basic Principles of Nutrition**

Introduction to principles of nutrition; basics of meal planning and preparation; safety techniques; personal nutrition planning. (Fall and Spring)

CTP 212 Basic Cooking Skills

Pr. 102 or equivalent

Recognition of different utensils/cookware required for meal preparation; recognition and demonstration of different preparation techniques; demonstration of cooking safety; how to stock a kitchen; how to cook for one, two, three or more. (Fall and Spring)

CTP 252 Nutrition Management

Pr. 102 or equivalent

Expansion of personal cooking techniques and recipes; advances meal planning strategies. (Fall and Spring)

RELATIONSHIPS, COMMUNICATION AND CONFLICT MANAGEMENT**CTP 103 Building Personal Relationships**

Introduction to methods for building and maintaining personal relationships; relationship etiquette; safe dating habits; how to manage conflict in personal relationships; emotional health. (Fall and Spring)

CTP 113 Social Communication

Exploration of different forms of social communication; formal vs. informal communication; assertive communication; active listening; conversation skills. (Fall and Spring)

CTP 143 Basics of Relationship Building: An Overview

Guided review of ICS learning objectives related to building and maintaining healthy relationships in college. (Summer)

CTP 203 Principles of Relating to People and Resolving Conflicts

Pr. 103 or equivalent

Expansion of conflict resolution and relationship building skills; strategies for communication about personally charged topics; recognition of conflict management supports. (Fall and Spring)

CTP 213 The Impact of Culture on Relationships

Introduction to different cultural differences that can impact personal relationships and community interaction.

CTP 243 Maintaining Relationships: An Overview

Guided review of advanced learning objectives related to relationship building and maintenance. (Summer)

CTP 303 Advanced Conflict Resolution

Pr. 203 or equivalent

Exploration of more involved resolution techniques; practical application in environment. (Fall and Spring)

CTP 343 Navigating Conflict

Guided review of learning objectives related to conflict management within personal relationships. (Summer)

CTP 363 Navigating Conflict II

Deeper exploration of conflict management strategies geared towards success in collegiate environment. (Summer)

ADVOCACY AND SELF-DETERMINATION**CTP 104 Introduction to Advocacy and Self-Determination**

Introduction to basic advocacy and self-determination principles; human rights and related responsibilities; civic/governmental structure; services and supports; personal responsibility. (Fall and Spring)

CTP 114 Public Speaking

Introduction to basic elements of public speaking; demonstration of techniques. (Fall and Spring)

CTP 124 Person Centered Planning

Introduction to different person centered planning models; elements of planning for one's own meeting; principles of developing a good team and ensuring positive outcomes. (Fall and Spring)

CTP 144 Self-Determination: An Overview

Guided review of learning objectives related to human rights, advocacy and self-determination and personal responsibility. (Summer)

CTP 164 Preparation for Sophomore Success

Exploration of academic and living strategies necessary for optimal performance in the sophomore year. (Summer)

CTP 204 Advocacy II

Pr. 104 or equivalent

Exploration of different types of advocacy (grassroots, legislative, etc.); understanding real life standards/personal outcome measures; self-directed services; support agencies in the community; natural support systems. (Fall and Spring)

CTP 214 Public Speaking II

Pr. 114 or equivalent

Expanded exploration of public speaking principles; development of community presentations. (Fall and Spring)

CTP 244 Advocacy: An Overview

Guided review of learning objectives related to advocacy movements, real life standards, self-directed supports and natural supports. (Summer)

CTP 264 Preparation for Junior Success

Exploration of academic and living strategies necessary for optimal performance in the junior year. (Summer)

CTP 314 History of Civil Rights

Introduction to basic time-lines of Civil Rights Movement related to gender, race and disability. (Fall and Spring)

CTP 404 Post Grad Seminar

Introduction to different types of public benefits; eligibility requirements; benefits management and resources; work incentives planning. (Fall and Spring)

PERSONAL PERFORMANCE AND ORGANIZATION**CTP 140 Freshman Summer Lab**

Guided review of strategies developed in CTP 190 related to direct application of well-being, nutrition, financial management, and home management skills within student's college environment. (Summer)

CTP 155 Principles of Home Management

Lab: Introduction to basic principles related to managing one's own home; household organization and management techniques. (Fall and Spring)

CTP 160 Freshman Summer Lab II

Continued review of strategies developed in CTP 140 and 190 related to direct application of well-being, nutrition, financial management, and home management skills within student's college environment. (Summer)

CTP 190 Freshman Personal Performance Lab

Direct application of well-being, nutrition, financial management, and home management skills within student's college environment. (Fall and Spring)

CTP 240 Sophomore Summer Lab

Guided review of strategies developed in CTP 290 related to direct application of well-being, nutrition, financial management, and home management skills within student's college environment. (Summer)

CTP 255 Home Organization and Planning

Lab: Expansion of home organization techniques and strategies; development of personalized organization schedules. (Fall and Spring)

CTP 260 Sophomore Summer Lab II

Continued review of strategies developed in CTP 240 and 290 related to direct application of well-being, nutrition, financial management, and home management skills within student's college environment. (Summer)

CTP 290 Sophomore Personal Performance Lab

Direct application of well-being, nutrition, financial management, and home management skills within student's college environment. (Fall and Spring)

CTP 340 Junior Summer Lab I

Guided review of strategies developed in CTP 390 related to direct application of well-being, nutrition, financial management, and home management skills within student's college environment. (Summer)

CTP 358 Junior Practicum

Preparation of elements of senior portfolio; guided review of foundational ICS learning objectives necessary for completion of certificate. (Fall and Spring)

CTP 360 Junior Summer Lab II

Continued review of strategies developed in CTP 340 and 390 related to direct application of well-being, nutrition, financial management, and home management skills within student's college environment. (Summer)

CTP 390 Junior Lab

Direct application of well-being, nutrition, financial management, and home management skills within student's college environment. (Fall and Spring)

CTP 440 Senior Summer Lab

Guided review of strategies developed in CTP 390 related to direct application of well-being, nutrition, financial management, and home management skills within student's college environment. (Summer)

CTP 458 Senior Practicum

Pr. 358, 391

Guided review of foundational ICS learning objectives necessary for completion of certificate; completion of Portfolio. (Fall and Spring)

CTP 460 Senior Summer Lab II

Continued review of strategies developed in CTP 340 and 390 related to direct application of well-being, nutrition, financial management, and home management skills within student's college environment. (Summer)

CTP 490 Senior Lab

Direct application of well-being, nutrition, financial management, and home management skills within student's college environment. (Fall and Spring)

FINANCE

CTP 106 Principles of Managing your Money

Introduction to financial supports; budgeting tools; check writing and account management; tracking personal income and expenses. (Fall and Spring)

CTP 116 Value of a Dollar

Recognition of denominations of money; money math; money vocabulary. (Fall and Spring)

CTP 146 Money Management: An Overview

Guided review of learning objectives related to budgeting, account management and income/expense tracking. (Summer)

CTP 166 Finances and Personal Performance

Continued exploration of foundational strategies necessary to be successful in collegiate environment. (Summer)

CTP 206 Financial Services and Supports

Pr. 106 or equivalent

Expansion of financial management techniques; recognition of financial scams and identity theft; saving techniques and planning; personal budgeting techniques; access to financial resources. (Fall and Spring)

CTP 216 Value of a Dollar II

Pr. 116 or equivalent

Explanation of money math skills; calculator math. (Fall and Spring).

CTP 246 Money Management II: An Overview

Guided review of learning objectives related to financial management, saving, and identification of financial resources. (Summer)

CTP 266 Finances and Personal Performance II

Continued exploration of advanced financial strategies necessary to be successful in collegiate environment. (Summer)

CTP 306 Advanced Financial Planning

Pr. 106, 206 or equivalents

Exploration of financial goal planning; credit card management; loans.

CTP 316 Value of a Dollar III

Pr. 116, 216 or equivalents

Expansion of money math skills; percentages; discount calculation; tips and taxes. (Fall and Spring)

CTP 326 Business Basics

Introduction to basic business terms; options for financing; common business problems; basic entrepreneurship and management skills; licenses and permits.

CTP 346 Advanced Money Management: An Overview

Guided review of advanced learning objectives related to financial goal planning. (Summer)

CTP 366 Advanced Financial Personal Performance

Continued exploration of advanced financial planning strategies necessary to be successful in post-collegiate environment. (Summer)

CAREER EXPLORATION AND BUSINESS DEVELOPMENT**CTP 107 Understanding Personal Value to your Community**

Exploration of community needs; existing resources and organizations; responsibilities related to being a member of one's community; recognition of personal strengths; principles of volunteering; universal policies of community organization. (Fall and Spring)

CTP 117 Marketing Yourself

Recognition of positive self-image and esteem; communication of personal strengths and skills; resume building; interviewing skills; communication skills; employment supports; time management. (Fall and Spring)

CTP 207 Career Exploration

Pr. 117 or equivalent

Exploration of long-term and short-term goals; strategies for optimizing personal strengths; communication; OSHA/Bloodborne Pathogens; alternative resume formats; job search techniques. (Fall and Spring)

CTP 247 Summer Career Exploration

Guided review of learning objectives related to short and long-term career goals; exploration of potential work sites. (Summer)

CTP 267 Summer Career Exploration II

Continued guided support of personal career goals and performance. (Summer)

CTP 307 Building Employment Skills

Pr. 207 or equivalent

Building employment skills related to time management, work ethic, company rules/regulations/policies; workplace safety; common entry level jobs.

CTP 357 Junior Internship/Service Learning

Pr. 117, 207, 307 or equivalents

Review of employment or service learning skills specific to field of interest; exploration of potential campus and community sites. (Fall and Spring)

CTP 457 Senior Internship

Pr. 117, 207, 307 357

Supported internship at site of choice on campus or in community.

ICS CONCENTRATIONS:

CTP 392 Business Seminar

Exploration and identification of micro-enterprise/entrepreneurial goals.

CTP 393 Career Seminar

Exploration and identification of career goals and action steps required to move closer to goals.

CTP 394 Civic Life Seminar

Exploration and identification of civic engagement and community involvement goals; exploration of local, state, and national government programs like Americorps, Seniorcorps, NC Citizen Corps, etc.

CTP 398 Summer ICS Concentration Seminar

Guided support of learning objectives related to student's chosen ICS concentration. (Summer)

CTP 399 Summer ICS Concentration Seminar II

Continued guided support of learning objectives related to student's chosen ICS concentration. (Summer)

CTP 491 Advanced Business Seminar

Pr. 392

Development of business plan; identification of supports necessary to support post-graduate micro-enterprise activity.

CTP 492 Advanced Career Seminar

Pr. 393

Intense exploration of advanced steps required to move closer to career goals, including identification of post-graduate supports for career related schooling, internships, etc.

CTP 493 Advanced Civic Life Seminar

Pr. 394

Expansion of understanding of civic engagement and community involvement opportunities; active engagement in preferred activities; planning for post-graduate involvement in programs of choice.

CTP 498 Summer ICS Concentration Seminar I

Guided support of learning objectives related to student's chosen ICS concentration. (Summer)

CTP 499 Summer ICS Concentration Seminar II

Continued guided support of learning objectives related to student's chosen ICS concentration. (Summer)

DIMENSIONS OF CAMPUS AND COMMUNITY LIVING**CTP 148 Summer Involvement Planning**

Guided support of learning objectives related to campus/community involvement. (Summer)

CTP 158 Basics of Getting Where you Want to go

Introduction to potential modes of transportation on campus and in community; transportation safety; practical application of knowledge.

CTP 168 Maintaining Summer Involvement

Continued support of personal campus/community involvement in goals and planning. (Summer)

CTP 248 Summer Involvement Planning II

Guided support of learning objectives related to campus/community involvement. (Summer)

CTP 258 Making the most of Transportation

Expansion of basic transportation knowledge; development of techniques/strategies that will increase personal accessibility.

CTP 268 Maintaining Summer Involvement II

Continued support of personal campus/community involvement in goals and planning.
(Summer)

CTP 159 Campus and Community Involvement

Introduction to planning/scheduling strategies; exploration of personal interests and desires; community safety; building relationships within community; leisure education.

CTP 259 Campus and Community Involvement II

Expansion of planning and involvement strategies identified in 159.

SELF-DIRECTED STUDY**CTP 349 Summer Self-Directed Studies I**

Guided review and support of learning objectives and goals addressed in CTP 391.
(Summer)

CTP 369 Summer Self-Directed Studies II

Guided review and support of learning objectives and goals addressed in CTP 349 and 391. (Summer)

CTP 391 Junior Life Planning Seminar

Exploration and determination of Life Plan- personal supports necessary to live a fully engaged life in community of choice; crosswalk to portfolio elements.

CTP 449 Post-Grad Self-directed Studies I

Guided review and support of goals and planning addressed in CTP 459. (Summer)

CTP 459 Community Inclusion Planning for Post-Grad Life

Application of life plan as determined in 391- exploration of post-grad supports necessary for successful engagement in life after college.

CTP 469 Summer Self-Directed Studies II

Guided review and support of goals and planning addressed in CTP 449 and 459.
(Summer)

ELECTIVES RELATED TO ICS CONCENTRATION

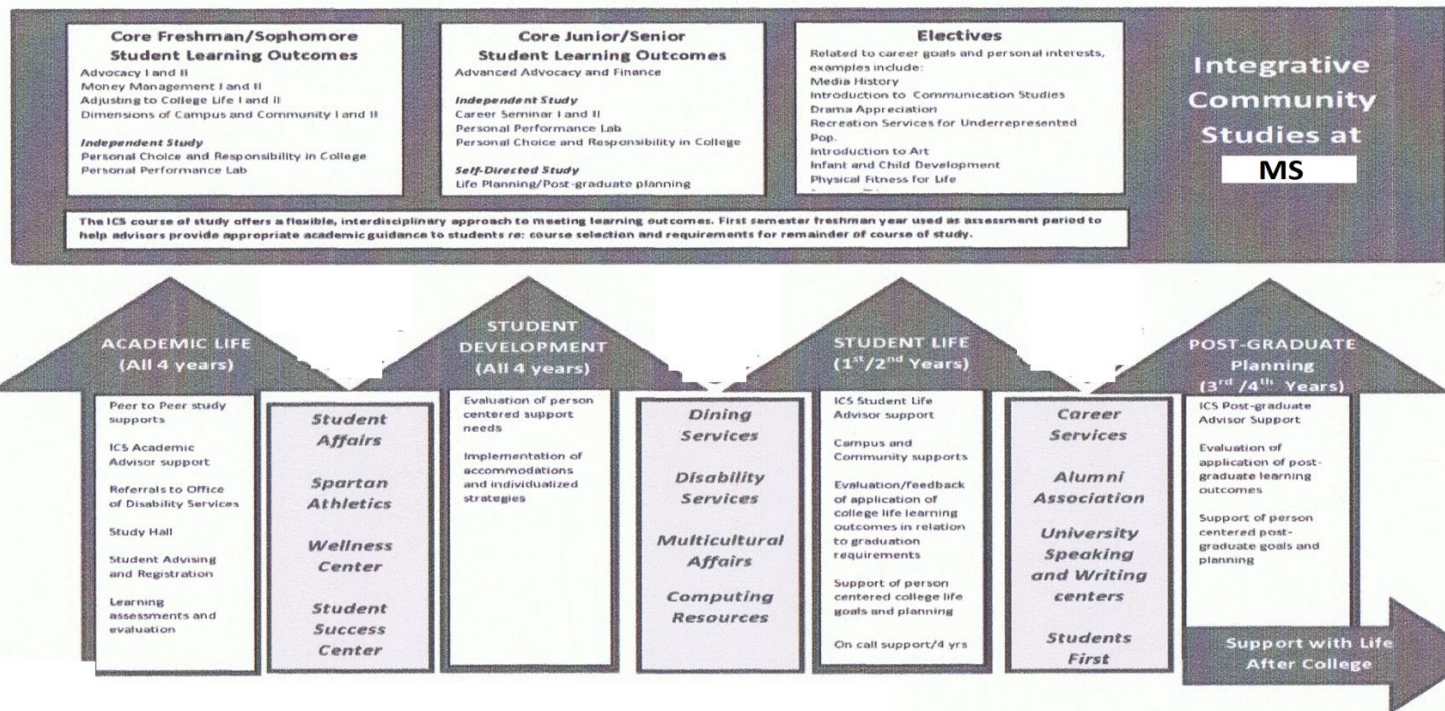
Credits required in degree-track courses related to student's ICS concentration, or independent field-work related to concentration.

GENERAL ELECTIVES

Credits required in area of interest outside of ICS concentration.

Appendix C: MS Course of Study Schematic

The Course of Study-At a Glance



Appendix D: Data Collection Materials

Basic Demographic Information for Informants

-Administered one time for each key participant interviewed during the initial interview

1. What is your name?
2. What do you prefer to be called?
3. What year are you in the BA program?
4. Can you please tell me a telephone number where I can contact you?
5. Can you please tell me an email address where I can contact you?
6. Do you live alone or with someone?
 - a. Do you live on campus?
 - b. If you do not live on campus, do you live far from here?

Initial Interviews for Key Informants

-Administered one time at the commencement of participation

Life Goals and School

1. When you were younger, what did you want to be when you grew up?
2. Why did you decide to go to college?
3. How did you make that decision?
4. How did you prepare to transition from high school to college? (*Prompting: Who helped you? What did you do at school to prepare you for high school? How did you prepare at home?*)
5. Please tell me about how that transition went or how it is going. (*Prompting: Do you feel that you made a successful transition to college? How are you adjusting to school?*)
6. Do you have friends who went to college?
7. Now that you are in college, what do you want to be?
8. What would you like to get out of your experience here at BA and UNCG?
9. How have you enjoyed school so far?
10. Have you had any major experiences you'd like to share with me?
11. Where do you see yourself in 5 years?
12. In 10 years?

Identity

13. How do you feel about being a student?

14. Do you consider yourself a college student?

15. What IS a college student? (*Prompting: What are their goals? What do they like to do?*)

Observation Guide

This guide is to be incorporated into the researcher's field notes during observations of key participants. Allow the participant(s) to speak and act freely. The purpose of the observation is to take notes of what occurs while you are with him/her/them in the natural environment.

- Date
- Time
- Participant Code
- Location(s) of Observation
- Contextual information
 - Physical environment
 - Other people present
 - What activities are occurring during the observation? (Class, hanging out with friends, going to the gym, etc.)
 - Who has chosen these activities? (Has the participant chosen them for him/herself or has CCS/SDS/teachers/parents chosen them?)
 - What is your role in this observation? (Active or passive? Etc.)
 - Other relevant contextual information (How does the participant seem to be feeling today? Has a major event occurred or is one coming up? Is this a typical day for the participant?)
 - Comments/questions/thoughts for analysis
 - Ideas for probing in next interview

Remember! Set up the next observation/interview with participant prior to leaving.

References

- American Association on Intellectual and Developmental Disabilities. (2013). Definition of intellectual disability. Retrieved from http://www.aaidd.org/content_100.cfm?navID=21
- Alsaker, S., & Josephsson, S. (2003). Negotiating occupational identities while living with chronic rheumatic disease. *Scandinavian Journal of Occupational Therapy*, 10(4), 167-176.
- Anctil, T. M., Ishikawa, M. E., & Scott, A. T. (2008). Academic identity development through self-determination: Successful college students with learning disabilities. *Career Development for Exceptional Individuals*, 31(3), 164-174.
- Asaba, E., & Jackson, J. (2011). Social ideologies embedded in everyday life: A narrative analysis about disability, identities, and occupation. *Journal of Occupational Science*, 18(2), 139-152.
- Bagatell, N. (2007). Orchestrating voices: autism, identity and the power of discourse. *Disability & Society*, 22(4), 413-426.
- Baglieri, S., Valle, J. W., Connor, D. J., & Gallagher, D. J. (2011). Disability studies in education: The need for a plurality of perspectives on disability. *Remedial and Special Education*, 32(4), 267-278.
- Bailliard, A. L., Aldrich, R. M., & Dickie, V. A. (2013). Ethnography and the transactional study of occupation. In M. P. Cutchin & V. A. Dickie (Eds.), *Transactional perspectives on occupation* (pp. 157-168). New York, NY: Springer.
- Bratun, U. & Asaba, E. (2008). From individual to communal experiences of occupation: Drawing upon Qi Gong practices. *Journal of Occupational Science*, 15(2), 80-86.
- Braveman, B., & Helfrich, C. A. (2001). Occupational identity: Exploring the narratives of three men living with AIDS. *Journal of Occupational Science*, 8(2), 25-31.
- Causton-Theoharis, J., Ashby, C., & DeClouette, N. (2009). Relentless optimism: Inclusive postsecondary opportunities for students with significant disabilities. *Journal of Postsecondary Education and Disability*, 22(2), 88-105.
- Carolina Institute for Developmental Disabilities (2013a). *LEND - Leadership Education in Neurodevelopmental Disorders*. Retrieved from <http://www.cidd.unc.edu/about/lend/>
- Carolina Institute for Developmental Disabilities (2013b). *North Carolina Postsecondary Education Alliance*. Retrieved from <http://www.cidd.unc.edu/psea/>

- Casale-Giannola, D., & Kamens, M. W. (2006). Inclusion at a university: Experiences of a young woman with Down Syndrome. *Mental Retardation*, 44(5), 344-352.
- Chiang, H.-M., Cheung, Y. K., Hickson, L., Xiang, R., & Tsai, L. Y. (2012). Predictive factors of participation in postsecondary education for high school leavers with autism. *Journal of Autism and Developmental Disorders*, 42, 685-696.
- Christiansen, C. H. (1999). Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning, 1999 Eleanor Clarke Slagle Lecture. *American Journal of Occupational Therapy*, 53(6), 547-558.
- Christiansen, C. (2000). Identity, personal projects and happiness: Self construction in everyday action. *Journal of Occupational Science*, 7(3), 98-107.
- Christiansen, C. H., & Townsend, E. A. (2004). The occupational nature of communities. In C. H. Christiansen & E. A. Townsend (Eds.), *Introduction to occupation: The art and science of living* (pp. 141-172). Upper Saddle River, NJ: Prentice Hall.
- Cutchin, M. P. (2004). Using Deweyan philosophy to rename and reframe adaptation-to-environment. *American Journal of Occupational Therapy*, 58, 303-312.
- Cutchin, M. P. (2007). From society to self (and back) through place: Habit in transactional context. *OTJR: Occupation, Participation and Health*, 27, 50S-59S.
- Cutchin, M. P. (2012). The art and science of occupation: Nature, inquiry, and the aesthetics of living. *Journal of Occupational Science*. Advance online publication. doi: 10.1080/14427591.2012.744290
- Cutchin, M. P., & Dickie, V. A. (2012). Transactionalism: Occupational science and the pragmatic attitude. In G. Whiteford & C. Hocking (Eds.), *Occupational science: Society, inclusion, participation* (pp. 23-37). Hoboken, NJ: Wiley-Blackwell.
- Cutchin, M. P. & Dickie, V. A. (2013). Transactional perspectives on occupation: An introduction and rationale. In M. P. Cutchin & V. A. Dickie (Eds.), *Transactional perspectives on occupation* (pp. 1-10). New York, NY: Springer.
- Developmental Disabilities Assistance and Bill of Rights Act of 2000 (2000). The Developmental Disabilities Assistance and Bill of Rights Act of 2000. Retrieved from <http://www.acf.hhs.gov/programs/aidd/resource/dd-act>
- Dickie, V. A. (2003). Establishing worker identity: A study of people in craft work. *American Journal of Occupational Therapy*, 57(3), 250-261.
- Dickie, V., Cutchin, M. P., & Humphry, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science*, 13(1), 83-93.

- Dolyniuk, C. A., Kamens, M. W., Corman, H., DiNardo, P. O., Totaro, R. M., & Rockoff, J. C. (2002). Students with developmental disabilities go to college: Descriptions of a collaborative transition project on a regular college campus. *Focus on Autism and Other Developmental Disabilities, 17*(4), 236-241.
- Eidelman, S. M. (2011). The reauthorization of IDEA 2004 and its impact on postsecondary opportunities for people with intellectual disabilities. *Think College Insight Brief* (Issue No. 7). Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Finn, D., Getzel, E. E., & McManus, S. (2008). Adapting the self-determined learning model for instruction of college students with disabilities. *Career Development for Exceptional Individuals, 31*(2), 85-93.
- Furgang, E. (2006). *Time use of adults with developmental disabilities*. Unpublished master's thesis, University of New Mexico, Albuquerque.
- Getzel, E. E., & Thoma, C. A. (2008). Experiences of college students with disabilities and the importance of self-determination in higher education settings. *Career Development for Exceptional Individuals, 31*(2), 77-84.
- Gilmore, D. S., Bose, J., & Hart, D. (2001). Postsecondary education as a critical step toward meaningful employment: Vocational rehabilitation's role. *Research to Practice, 7*(4), 1-4.
- Grigal, M., Hart, D., & Lewis, S. (2012). A prelude to progress: The evolution of postsecondary education for students with intellectual disabilities. *Think College Insight Brief* (Issue No. 12). Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Grigal, M., Hart, D., & Migliore, A. (2011). Comparing the transition planning, postsecondary education, and employment outcomes of students with intellectual and other disabilities. *Career Development for Exceptional Individuals, 34*(1), 4-17.
- Grigal, M., Hart, D., & Weir, C. (2012). A survey of postsecondary education programs for students with intellectual disabilities in the United States. *Journal of Policy and Practice in Intellectual Disabilities, 9*(4), 223-233.
- Grigal, M., Neubert, D. A., & Moon, M. S. (2002). Postsecondary options for students with significant disabilities. *Teaching Exceptional Children, 35*(2), 68-73.
- Hamill, L. B. (2003). Going to college: The experiences of a young woman with Down Syndrome. *Mental Retardation, 41*(5), 340-353.
- Hart, D., Grigal, M., & Weir, C. (2010). Expanding the paradigm: Postsecondary education options for individuals with autism spectrum disorder and intellectual

- disabilities. *Focus on Autism and Other Developmental Disabilities*, 25(3), 134-150.
- Hasselkus, B. R., & Murray, B. J. (2007). Everyday occupation, well-being, and identity: The experience of caregivers in families with dementia. *American Journal of Occupational Therapy*, 61, 9-20.
- Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 24(2), 77-88.
- Higher Education Opportunity Act of 2008 (2008). Higher Education Opportunity Act - 2008. Retrieved from <http://www2.ed.gov/policy/highered/leg/hea08/index.html>
- Hocking, C. (2000). Occupational science: A stock take of accumulated insights. *Journal of Occupational Science*, 7(2), 58-67.
- Holland, D. C., & Eisenhart, M. A. (1990). *Educated in romance: Women, achievement, and college culture*. Chicago, IL: University of Chicago Press.
- Holland, D., Lachicotte, W., Jr., Skinner, D., & Cain, C. (1998). *Identity and agency in cultural worlds*. Cambridge, MA: Harvard University Press.
- Humphry, R. (2005). Model of processes transforming occupations: Exploring societal and social influences. *Journal of Occupational Science*, 12(1), 36-44.
- Huot, S., & Laliberte Rudman, D. (2010). The performances and places of identity: Conceptualizing intersections of occupation, identity and place in the process of migration. *Journal of Occupational Science*, 17(2), 68-77.
- Individuals with Disabilities Education Improvement Act of 2004, 20 U.S.C. § 1400 *et seq.* (2004).
- Jakobsen, K. (2001). Employment and the reconstruction of self. A Model of space for maintenance of identity by occupation. *Scandinavian Journal of Occupational Therapy*, 8(1), 40-48.
- Johnson, D. R., & Nord, D. (2010/11, Autumn/Winter). Students with disabilities in higher education: Participating in America's future. *Impact: Feature Issue on Postsecondary Education and Students with Intellectual, Developmental and Other Disabilities*, 23(3), 2-3.
- Kids Together, Inc. (2010). *What is inclusion?* Retrieved from Kids Together, Inc.: <http://www.kidstogether.org/inclusion.htm>
- Kielhofner, G. (2002). *Model of human occupation: Theory and application* (3rd ed.). Philadelphia, PA: F.A. Davis.

- Kuh, G. D. (1995). The other curriculum: Out-of-class experiences associated with student learning and personal development. *Journal of Higher Education*, 66(2), 123-155.
- Laliberte-Rudman, D. (2002). Linking occupation and identity: Lessons learned through qualitative exploration. *Journal of Occupational Science*, 9(1), 12-19.
- Laliberte Rudman, D., & Dennhardt, S. (2008). Shaping knowledge regarding occupation: Examining the cultural underpinnings of the evolving concept of occupational identity. *Australian Occupational Therapy Journal*, 55, 153-162.
- Lennox Terrior, J., & Leonard, D. (2010). Motivation of paid peer mentors and unpaid peer helpers in higher education. *International Journal of Evidence Based Coaching and Mentoring*, 8(1), 85-103.
- Lewis, M. A., Lewis, C. E., Leake, B., King, B. H., & Lindemann, R. (2002). The quality of health care for adults with developmental disabilities. *Public Health Reports*, 117(2), 174-184.
- Lindstrom, L., Doren, B., & Miesch, J. (2011). Waging a living: Career development and long-term employment outcomes for young adults with disabilities. *Exceptional Children*, 77(4), 423-434.
- Longmore, P. K. (2000). Disability policy and politics: Considering consumer influences. *Journal of Disability Policy Studies*, 11(1), 36-44.
- Magnus, E. (2001). Everyday occupations and the process of redefinition: A study of how meaning in occupation influences redefinition of identity in women with a disability. *Scandinavian Journal of Occupational Therapy*, 8(3), 115-124.
- Marcotte, D. E., Bailey, T., Borkoski, C., & Kienzel, G. S. (2005). The returns of a community college education: Evidence from the National Education Longitudinal Survey. *Educational Evaluation and Policy Analysis*, 27(2), 157-175.
- McCarthy, H. (2003). The disability rights movement: Experiences and perspectives of selected leaders in the disability community. *Rehabilitation Counseling Bulletin*, 46(4), 209-223.
- Migliore, A., Butterworth, J., & Hart, D. (2009). Postsecondary education and employment outcomes for youth with intellectual disabilities. *Think College Fast Facts* (Issue No. 1). Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- NC Department of Health and Human Services. (2013). *Community alternatives program for persons with mental retardation/developmental disabilities*. Retrieved from <http://www.ncdhhs.gov/mhddsas/providers/CAPMRDD/index.htm>

- Neubert, D. A., Moon, M. S., Grigal, M., & Redd, V. (2001). Post-secondary educational practices for individuals with mental retardation and other significant disabilities: A review of the literature. *Journal of Vocational Rehabilitation, 16*, 155-168.
- Newman, L., Wagner, M., Cameto, R., & Knokey, A.-M. (2009). *The Post-High School Outcomes of Youth with Disabilities up to 4 Years after High School. A Report from the National Longitudinal Transition Study-2 (NLTS2)* (NCSE 2009-3017). Menlo Park, CA: SRI International.
- Newman, L., Wagner, M., Cameto, R., Knokey, A.-M., & Shaver, D. (2010). *Comparisons across time of the outcomes of youth with disabilities up to 4 years after high school: A report of findings from the National Longitudinal Transition Study (NLTS) and the National Longitudinal Transition Study-2 (NLTS2)* (NCSE 2010-3008). Menlo Park, CA: SRI International.
- Newman, L., Wagner, M., Knokey, A.-M., Marder, C., Nagle, K., Shaver, D., Wei, X., with Cameto, R., Contreras, E., Ferguson, K., Greene, S., & Schwarting, M. (2011). *The post-high school outcomes of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2)* (NCSE 2011-3005). Menlo Park, CA: SRI International.
- National Dissemination Center for Children with Disabilities. (2010). *Special education*. Retrieved from <http://nichcy.org/schoolage/iep/iepcontents/specialeducation#mods>
- Noyes, D. A., & Sax, C. L. (2004). Changing systems for transition: Students, families, and professionals working together. *Education and Training in Developmental Disabilities, 39*(1), 35-44.
- Papay, C. K., & Bambara, L. M. (2011). Postsecondary education for transition-age students with intellectual and other developmental disabilities: A national survey. *Education and Training in Autism and Developmental Disabilities, 46*(1), 78-93.
- Phelan, S., & Kinsella, E. A. (2009). Occupational identity: Engaging socio-cultural perspectives. *Journal of Occupational Science, 16*(2), 85-91.
- Prince-Hughes, D. (2003). Understanding college students with autism. *Chronicle of Higher Education, 49*(17), B16-B17.
- Redd, V. A. (2004). A public school-sponsored program for students ages 18-21 with significant disabilities in a community college campus: A case-study. *Dissertation Abstracts International, 65* (07), 2561A. (UMI No. 3139063)
- Rimmer, J. H., & Yamaki, K. (2006). Obesity and intellectual disability. *Mental Retardation and Developmental Disabilities Research Reviews, 12*(1), 22-27.

- Roberts, K. D. (2010). Topic areas to consider when planning transition from high school to postsecondary education for students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 25(3), 158-162.
- Robertson, S. M. & Ne'eman, A. D. (2008). Autistic acceptance, the college campus, and technology: Growth of neurodiversity in society and academia. *Disability Studies Quarterly*, 28(4). Retrieved from <http://dsq-sds.org/article/view/146/146>
- Sanford, C., Newman, L., Wagner, M., Cameto, R., Knokey, A.-M., & Shaver, D. (2011). *The post-high school outcomes of young adults with disabilities up to 6 years after high school: Key findings from the National Longitudinal Transition Study-2 (NLTS2)* (NCSE 2011-3004). Menlo Park: CA: SRI International.
- Schmidt, P. (2005, February 18). From special ed to higher ed. *The Chronicle of Higher Education*, 51(24). Retrieved from <http://chronicle.com.libproxy.lib.unc.edu/article/From-Special-Ed-to-Higher-Ed/21991/>
- Schwandt, T. A. (2007). *The SAGE dictionary of qualitative inquiry* (3rd ed.). Los Angeles, CA: Sage Publications.
- Scotch, R. K. (1989). Politics and policy in the history of the disability rights movement. *The Milbank Quarterly*, 67(Suppl. 2, Part 2). 380-400.
- Scotch, R. K. (2000). Disability policy: An eclectic overview. *Journal of Disability Policy Studies*, 11(1), 6-11.
- Segal, R. (2005). Occupations and identity in the life of a primary caregiving father. *Journal of Occupational Science*, 12(2), 82-90.
- Shogren, K. A., & Plotner, A. J. (2012). Transition planning for students with intellectual disability, autism, or other disabilities: Data from the National Longitudinal Transition Study-2. *Intellectual and Developmental Disabilities*, 50(1), 16-30.
- Smith Lee, S. (2009). Overview of the federal Higher Education Opportunity Act reauthorization. *Think College Insight Brief* (Issue No. 1). Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Stake, R. E. (2003). Case studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (2nd ed., pp. 134-164). Thousand Oaks, CA: Sage Publications.
- Stodden, R. A., & Mruzek, D. W. (2010). An introduction to postsecondary education and employment of persons with autism and developmental disabilities. *Focus on Autism and Other Developmental Disabilities*, 25(3), 131-133.
- Stodden, R. A., & Whelley, T. (2004). Postsecondary education and persons with intellectual disabilities: An introduction. *Education and Training in Developmental Disabilities*, 39(1), 6-15.

- Sutherland, G., Couch, M. A., & Iacono, T. (2002). Health issues for adults with developmental disability. *Research in Developmental Disabilities*, 23(6), 422-445.
- Think College (2012). *Glossary*. Retrieved from <http://www.thinkcollege.net/about-us/glossary>
- Think College (2013). *Think College Program Database*. Retrieved from <http://www.thinkcollege.net/databases/programs-database?view=programsdatabase>
- Thoma, C., Austin, K., Achola, E., Batalo, C., Carlson, D., Boyd, K., ... Wolfe, D. (2012). The state of postsecondary education for persons with intellectual disabilities: What are the perceptions of key stakeholders? *Creative Education*, 3, 1122-1129.
- Thoma, C. A., Lakin, K. C., Carlson, D., Domzal, C., Austin, K., & Boyd, K. (2011). Participation in postsecondary education for students with intellectual disabilities: A review of the literature 2001-2010. *Journal of Postsecondary Education and Disability*, 24(3), 175-191.
- Tresch, J. (2001). On going native: Thomas Kuhn and anthropological method. *Philosophy of the Social Sciences*, 31(3), 302-322.
- Uditsky, B. & Hughson, E. (2012). Inclusive postsecondary education—An evidence-based moral imperative. *Journal of Policy and Practice in Intellectual Disabilities*, 9(4), 298-302.
- Unruh, A. M. (2004). Reflections on: “So...what do you do?” Occupation and the construct of identity. *Canadian Journal of Occupational Therapy*, 71(5), 290-295.
- Unruh, A. M.; Versnel, J., & Kerr, N. (2002). Spirituality unplugged: A review of commonalities and contentions, and a resolution. *Canadian Journal of Occupational Therapy*, 69(1), 5-19.
- U.S. Department of Education, National Center for Education Statistics. (2012). *Digest of Education Statistics, 2011* (NCES 2012-001). Retrieved March 12, 2013 from <http://nces.ed.gov/fastfacts/display.asp?id=98>
- VanBergeijk, E. O., & Cavanagh, P. K. (2012). Brief report: New legislation supports students with intellectual disabilities in post-secondary funding. *Journal of Autism and Developmental Disorders*, 42, 2471-2475.
- Vogt, W. P. (2005). *Dictionary of statistics and methodology* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Watson, N. (2012). Theorising the lives of disabled children: How can disability theory help? *Children and Society*, 26, 192-202.

- Wehmeyer, M. L. (2004). Beyond self-determination: Causal Agency Theory. *Journal of Developmental and Physical Disabilities*, 16(4), 337-359.
- Wolcott, H. F. (2008). *Ethnography: A way of seeing* (2nd ed.). New York, NY: AltaMira Press.
- Wolcott, H. F. (2010). *Ethnography lessons: A primer*. Walnut Creek, CA: Left Coast Press.
- Zafft, C., Hart, D., & Zimbrich, K. (2004). College career connection: A study of youth with intellectual disabilities and the impact of postsecondary education. *Education and Training in Developmental Disabilities*, 39(1), 45-53.