By the Bootstraps:
Social Entrepreneurs with Intellectual Disabilities
and the Reification of Success

BY

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DISSERTATION
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DEDICATION

Dedication seems a fitting way to preface this dissertation. As the third generation of women in my family to pursue a doctorate, I thought that I knew what to expect. However, I could not have expected life to intervene the way it has, both testing my dedication to and understanding of Disability Studies. I feel the need to recognize all that has been lost and gained throughout this process.

The work that follows would not have been possible without my family: my mother who taught me to explore the world through the eyes of a researcher, and my father who taught me the beauty and purpose of writing. Most importantly, none of this would have been possible without my twin sister, Sarah, who I would like to thank for joining me in this journey – although at times unwittingly. Our twinship has informed so much of my work and her support has been invaluable. To my twin, I am grateful and appreciative, but most of all I am deeply proud to share this life with you.

In addition to my family, I would like to thank those stalwart friends and loved ones who have been there for me through surgeries and celebrations, floods and a Hundred Miles of Nowhere. Your kindness, love, and consideration have meant the world to me. Jen and Maria, I don’t know what I did to deserve your presence in my life, but you have made me a better person and scholar. Thank you. For being the amazingly beautiful women you are.

Last, but certainly not least, I have to thank Winston. So much more than a dog, he is the piece of myself that I never knew was missing. While his laying on my keyboard was not always conducive to writing, Winston helped me learn that there is more to life than work.
ACKNOWLEDGEMENTS

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<td>ABLE</td>
<td>Achieving a Better Live Experience Act</td>
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<td>ADA</td>
<td>Americans with Disabilities Act</td>
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<tr>
<td>CFO</td>
<td>Chief Financial Officer</td>
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<tr>
<td>CIL</td>
<td>Center for Independent Living</td>
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<tr>
<td>CILA</td>
<td>Community Integrated Living Arrangement</td>
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<tr>
<td>COO</td>
<td>Chief Operating Officer</td>
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<td>DRS</td>
<td>Department of Rehabilitation Services</td>
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<td>EEM</td>
<td>Entrepreneurial Event Model</td>
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<td>GAO</td>
<td>Government Accountability Office</td>
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<td>IAMC</td>
<td>Illinois Association of Microboards and Cooperatives</td>
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<td>IEP</td>
<td>Individualized Education Program</td>
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<td>I/DD</td>
<td>Intellectual and Developmental Disability</td>
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<td>ID</td>
<td>Intellectual Disability</td>
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<td>IDA</td>
<td>Individual Development Account</td>
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<td>IQ</td>
<td>Intellectual Functioning Quotient</td>
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<td>IRB</td>
<td>Institutional Review Board</td>
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<td>IRWE</td>
<td>Impairment-Related Work Expenses</td>
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<td>MAP</td>
<td>Making Action Plans</td>
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<td>PA</td>
<td>Personal Assistant</td>
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<tr>
<td>PASS</td>
<td>Plan for Achieving Self-Support</td>
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<tr>
<td>PATH</td>
<td>Planning Alternative Tomorrows with Hope</td>
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<td>PTI</td>
<td>Participation Through Innovation Research Project</td>
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<td>RSA</td>
<td>Rehabilitation Services Administration</td>
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<td>SBA</td>
<td>Small Business Administration</td>
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<td>SBDC</td>
<td>Small Business Development Center</td>
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<td>Abbreviation</td>
<td>Full Form</td>
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<td>SEA</td>
<td>Self-Employment Assistance</td>
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<td>SGA</td>
<td>Substantial Gainful Activity</td>
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<td>SSA</td>
<td>Social Security Administration</td>
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<td>SSI</td>
<td>Social Security Insurance</td>
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<tr>
<td>SSDI</td>
<td>Social Security Disability Insurance</td>
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<tr>
<td>TBP</td>
<td>Theory of Planned Behavior Model</td>
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<td>UN CRPD</td>
<td>United Nations Convention on the Rights of Persons with Disabilities</td>
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<td>VR</td>
<td>Vocational Rehabilitation</td>
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SUMMARY

Social entrepreneurship is a growing trend for people with intellectual disabilities (ID). This reflects a shift in contemporary policy towards entrepreneurship and self-employment as viable employment option for people with disabilities in general; a strategy which is intended to promote autonomy and reduce dependence on entitlement-based services as well as to reduce employment disparities and stimulate business and job creation. However, it is not well understood what exactly this means for people with ID involved in social entrepreneurial ventures. This dissertation research approached the issue by conducting dyadic interviews to explore how people with ID are participating and supported in social entrepreneurship. This dyadic approach involved conducting in-depth interviews with people with ID participating in social entrepreneurship, and also the person that they identified as being most instrumental in providing support. In exploring the experiences of social entrepreneurs with ID, interviews were structured around three foci of entrepreneurial research – motivation: why they act, management: how they act, and outcomes: what happens when they act. By drawing on Critical Disability Studies literature to interpret social entrepreneurship within a socio-political context, this research expands upon our understanding of “success” in social entrepreneurship in a way that not only contributes to disability theory and entrepreneurship theory, but also broadens our understanding of outcomes in employment for people with ID. Moreover, insight into how social entrepreneurship is being applied for this group can be used to influence social policy.
I. INTRODUCTION

The research presented here is an autonomous subcomponent of a larger project, Participation Through Innovation (PTI): Social Entrepreneurship as a Pathway to Employment for People with Disabilities. PTI began in June 2010 as a two-year pilot project funded through the University of Illinois at Chicago’s (UIC) Chancellor’s Discovery Fund for Multidisciplinary Pilot Research, striving to bridge the fields of Disability Studies and Entrepreneurial Studies in an effort to address a gap in the existing theory, policy, and practice (Caldwell, Parker Harris, & Renko, 2012, 2014; Parker Harris, Caldwell, & Renko, in press; Parker Harris, Renko, & Caldwell, 2013, 2014; Renko, Parker Harris, & Caldwell, 2014). PTI is the first empirical analysis of social entrepreneurship among people with disabilities, using a qualitative approach to explore the barriers and facilitators to social entrepreneurship through the use of focus groups with people with disabilities and interviews with key stakeholders working in the field. Given the increasing interest in social entrepreneurship observed in the intellectual disability (ID) community, it was vital that the voices and perspectives of people with ID themselves who are participating in social entrepreneurship be included in this research. However, there were concerns that a focus group environment might not be the best approach for gaining rich data on the topic for people with ID, who may experience different barriers and facilitators than social entrepreneurs with other disabilities. Accordingly, in-depth dyadic interviews were conducted with people with ID participating in social entrepreneurship and the person they identify as their key support. In exploring how people with ID are participating and supported in social entrepreneurship, this research was structured around three foci of entrepreneurial research – motivation: why they act, management: how they act, and outcomes: what happens when they act.
The first chapter presents a review of existing literature and key concepts at the intersection of Disability Studies and Entrepreneurial Studies, building upon the work of the larger project in bridging these fields by integrating scholarship in the field of intellectual disability research. This review of theoretical literature on disability, entrepreneurship, and citizenship in addition to research on disability employment, sources of support, interdependence, and self-determination provides context for the conceptual and theoretical frameworks underlie this research.

The second chapter outlines the methodological epistemology, approach, and techniques used in data collection and analysis. The methodological epistemology is rooted in Critical Disability Studies, which is distinguished from Disability Studies by its engagement with critical theory. Dyadic interviewing is a new approach to conducting in-depth interviews with people with ID developed specifically for this research that draws upon this distinction. Dyadic interviewing is a qualitative approach that recognizes there exists an interdependent relationship between individuals, embracing this phenomenon as a source of information rather than attempting to control for it. The interview structure consists of a dyad that includes the individual with ID and the person they identify as their key support person. Rich descriptions of participants with ID, their key support persons, and the social enterprises are presented in the third chapter to inform the analysis that follows.

The fourth chapter focuses on understanding the motivations behind people with ID participating in social entrepreneurship, or why they act. In particular, this chapter explores push-pull factors, the role of the social mission, and how support influences motivation. The fifth chapter focuses on understanding the management processes being used by people with ID, or how they act in negotiating between formal and informal systems of services and supports.
This chapter will also explore the barriers encountered in pursuing social entrepreneurship. In the sixth chapter, the focus centers on understanding outcomes as they pertain to social entrepreneurship for people with ID, or what happens when they act. In particular, this chapter will explore participants’ perceptions of profit, self-sufficiency, growth, and social innovation to challenge how outcomes are traditionally assessed in disability employment and entrepreneurship policy.

The final chapter presents a discussion of how motivation, management, and outcomes relate to the conceptualization of “success” in social entrepreneurship for people with ID participating in this research. This chapter will discuss implications beyond the current research to address the significance of these findings to the fields of Disability Studies and Entrepreneurial Studies, in particular with regards to steps for future research and development in intellectual disability research and disability employment policy.
II. REVIEW OF LITERATURE

A. Background

To date, little research exists on self-employment and entrepreneurship among people with disabilities. Further, many of these studies excluded individuals with ID. For example, Peter Blanck has studied employment and disability extensively over the course of his career; including a joint venture with David Braddock exploring the confluence of the Americans with Disabilities Act and integrated employment for people with ID (Blanck & Braddock, 1998). He was also principally involved in the seminal Iowa Entrepreneurs with Disabilities (EWD) study that provides a venerable foundation upon which to further empirical research in this area (Blanck, Sandler, Schmeling, & Schartz, 2000). However, the EWD study excluded individuals with congenital disabilities (55 individuals, 11.7%) and “mental retardation” (8 individuals, 1.7%) from interview participation (Blanck et al., 2000, p. 1648).

In the majority of scholarship on this topic, entrepreneurship is spoken of as a suggestion and much of the research is theoretical; arguing for policy directions without necessarily following programmatic implementation. As a result, little evidence-based research has been conducted on the motivation for, management process of, or outcomes of entrepreneurship for people with disabilities. Further, most of what evidence-based research has been done focuses on identifying barriers and establishing Vocational Rehabilitation (VR) case closure as a successful outcome to demonstrate that self-employment, not necessarily entrepreneurship, is a viable employment option for people with disabilities. In short, whereas research on social entrepreneurship is published elsewhere: Caldwell, K., Parker Harris, S., & Renko, M. (2012). The Potential of Social Entrepreneurship: Conceptual Tools for Applying Citizenship Theory to Policy and Practice. Intellectual & Developmental Disabilities, 50(6), 505-518; Parker Harris, S., Caldwell, K., & Renko, M. (in press). Entrepreneurship by any other name: Self-sufficiency versus innovation. Journal of Social Work in Disability & Rehabilitation; and Parker Harris, S., Renko, M., & Caldwell, K. (2013). Accessing Social Entrepreneurship: Perspectives of People with Disabilities and Key Stakeholders. Vocational Rehabilitation, 38, 35-48.

entrepreneurship and disability is nascent, when introducing ID to the discussion it becomes non-existent.

What follows is a review of existing literature relevant to the topic of social entrepreneurship and ID, predicated by the conceptual framework for this research, the introduction of integral key concepts, and the guiding theoretical framework. The literature review begins with an overview of main themes and information regarding disparities that provides background to understanding the issue of employment and disability in general. This is followed by a review of the opportunities and barriers to general employment as well as those opportunities and barriers specific to self-employment and entrepreneurship. The information presented in these sections will contribute to understanding the position of social entrepreneurship in contemporary policy, which must then be contextualized within perspectives on employment and intellectual disability. With the introduction of ID to this dialogue, issues are raised regarding the conflation of self-employment and social entrepreneurship. These issues must be informed by integrating entrepreneurship theory, in particular three foci of entrepreneurship research (motivation, management, and outcomes), and finally by unpacking the concept of “success” and the position of people with ID in society.

B. Conceptual Framework

At the outset, this dissertation research must first establish and build upon a synthesis of disability theory and entrepreneurship theory to incorporate ID literature and research, a theoretical intersection that has not been previously explored. In order to begin approaching the overarching objective of reifying “success” for people with ID involved in social entrepreneurial ventures, the subsequent review of literature begins by laying the foundation for understanding disability as it relates to employment and the factors leading to the contemporary policy shift
towards entrepreneurship for people with disabilities in general. An appreciation for the broader impact of these socio-political implications necessitates the contextualization of this discourse within literature on ID and employment; informing the current trend towards social entrepreneurship for people with ID. Integrating entrepreneurship theory allows this research to begin problematizing the construct of “success” and to use the foci of entrepreneurship research to structure exploration of that phenomenon as it applies to people with ID involved in social entrepreneurial ventures.

This synthesis of Disability Studies and entrepreneurship outlines the theoretical framework underpinning this research. Integrating these two disciplines makes it possible for one to inform the other and thereby address gaps in each field attendant to the question of entrepreneurship for people with disabilities. However, the location of ID is questionable in both disability theory (Carlson, 2010a; Chappell, 1998; Chappell, Goodley, & Lawthom, 2001; Goodley, 2001, 2004) and entrepreneurship theory, due to the emphasis placed on cognitive ability (Alvarez & Busenitz, 2001; R. A. Baron, 2007; R. A. Baron & Henry, 2010), and consequently ID becomes marginalized. As a result, our understanding of social entrepreneurship for people with disabilities, addressed by the larger research project (PTI), leaves the place of ID unclear. Accordingly, the conceptual framework driving this research entails the centering of ID, shifting its position from being marginal to being the focal point so that we might gain an understanding of how people with ID experience social entrepreneurship (Figure 1). Providing a more holistic perspective, this research will further advance our understanding of social entrepreneurship and people with disabilities in general, by being inclusive of ID issues and concerns.
Figure 1: Conceptual Framework

Disability Theory
(Place of ID questionable)

Entrepreneurship Theory
(Place of ID questionable)

Understanding social entrepreneurship for PWD in general
(Place of ID unclear)

Requires the centering of ID by contextualizing within ID research & literature

Understanding social entrepreneurship for people with ID

Understanding social entrepreneurship for people with disabilities, including people with ID
Theoretically, this research draws on Critical Disability Studies literature to interpret social entrepreneurship within a sociopolitical context. Entrepreneurship literature suggests that entrepreneurial opportunities can be identified at the intersection of enterprising individuals and the environment (Alvarez & Barney, 2004; Alvarez & Busenitz, 2001; Ardichvili, Cardozo, & Ray, 2003; R. A. Baron & Ensley, 2006; Gaglio & Katz, 2001; Kirzner, 1979; Ozgen & Baron, 2007; Shane, 2000; Shane & Venkataraman, 2000). In Disability Studies literature the social environment has been widely recognized as a core barrier to participation (Barnes & Mercer, 2005; Blanck, 2004; Blanck & Schartz, 2001; Fleischer & Zames, 2001; Hahn, 1985; Longmore & Umansky, 2001; National Council on Disability, 2005; OECD, 2007; Scotch, 2001; Siebers, 2001; Zarb, 1995). However, there is little understanding of how the social environment for people with disabilities can give rise to plentiful opportunities for social innovation.

The intersection of social entrepreneurship research and disability research is ripe for collaboration as insights from one field can help move the other forward. By incorporating a Disability Studies perspective into business theory, this research will create equally important and novel insights in the area of social entrepreneurship by expanding upon conceptualizations of “success” to include people with ID. This dissertation, in conjunction with the larger research project (PTI), will contribute to new theoretical and social policy knowledge in Disability Studies through applying a business theory lens to emancipatory disability research. Current adult employment research predominantly focuses on incentives, disincentives, barriers, and facilitators of “traditional” employment policies and practices (i.e., anti-discrimination, social security, welfare-to-work, rehabilitation training, and workplace supports). However, people with disabilities continue to experience widespread employment problems and economic disparity. Synergizing entrepreneurship theories (i.e., social value proposition, push-pull
motivation, and causation vs. effectuation) and theoretical approaches in Disability Studies (i.e., social model, social constructionism, human rights, self-determination, and interdependence), provides a relevant contribution to current gaps in the respective fields. Furthermore, introducing social entrepreneurship research to Disability Studies offers an important missing component that can better address current research challenges and present innovative policy solutions to increasing employment opportunities for people with disabilities.

The deconstruction of entrepreneurship into three foci (motivation, management, and outcomes) provides structure for incorporating ID. The elements of participation and support are used to further delineate and focus this research. While intended to be exploratory, given that this study is an area that has not previously been researched, it would otherwise run the risk of having a scope that is too broad to be feasible were it not for the guidance these frameworks impose.

C. **Introducing Key Concepts**

There are several key concepts integral to this research, which include both theoretical and operational definitions: social entrepreneurship, disability, intellectual disability, social support, interdependence, and self-determination. The introduction of these concepts not only provides tools with which to critically interpret the literature that follows, but also contributes substantively to the theoretical framework driving this research, and it will be referred to throughout analysis. First and foremost, a description of social entrepreneurship and how it differs from self-employment and entrepreneurship will establish the way in which this term will be operationalized. Similarly, perspectives on disability and intellectual disability are presented and informed by a Disability Studies ideology as the social model of disability enhances the use of social constructionism, and both perspectives provide justification for self-identification as an
act of empowerment but also to limit investigator bias. Social support is an important element in both entrepreneurship and ID research; both referring to social networks as well as formal and informal forms of support in complementary and contradictory ways. Perhaps most relevant to research on social entrepreneurs with ID is what has already been learned about the potential for social mobility and limitations of enclave environments among ethnic entrepreneurs. Ultimately, the concepts of interdependence and self-determination within ID literature and how they relate to a disability rights discourse in pursuit of independence have potential to contribute to and perhaps in some ways challenge existing knowledge of entrepreneurship.

1. **Self-employment, entrepreneurship and social entrepreneurship**

   Self-employment has been essential to the economic advancement and social mobility of ethnic groups and immigrants in the U.S. (T. Bates, 1997; Sanders & Nee, 1996; Waldinger, Aldrich, & Ward, 2000). Many immigrants come to the U.S. with substantial human capital, but find that while it has little value in the mainstream labor market, it can facilitate self-employment. Well-educated immigrants often start their own businesses because they have the skills and knowledge, but also because business ownership is often associated with economic advantage (Sanders & Nee, 1996). The promise of self-employment is upward social mobility – to empower the disadvantaged and downtrodden to lift themselves out of poverty in pursuit of the American Dream. Following in the proverbial footsteps of Horatio Alger (T. Bates, 1997; Sarachek, 1978), many of us are familiar with the classic “rags-to-riches” narrative of childhood poverty and disadvantage, motivating the protagonist to overcome the hardship of “traumatic deprivation” (Sarachek, 1978). However, in moving forward it is imperative that we take into consideration the extent to which power structures affect the integration of disadvantaged groups within social entrepreneurship (De Clercq & Honig, 2009).
Whereas self-employment refers to a sense of financial self-sustainability, it is innovation that distinguishes entrepreneurship from other forms of enterprise (Schumpeter, 2000; Shane & Venkataraman, 2000). Not everyone who starts a business is an entrepreneur. To be an entrepreneur, one’s business must have something innovative or change-oriented about it (Dees, 2001). In addition to the concept of innovation, the notion of opportunity has become central to contemporary definitions of entrepreneurship. While Schumpeter saw the entrepreneur as a change-maker, disrupting the socio-economic equilibrium through innovation, Drucker emphasized the view that the entrepreneur exploited opportunities that create change (Dees, 2001). Indeed, entrepreneurship relies upon opportunity recognition (R. A. Baron & Ensley, 2006), which involves the existence of, the discovery of, and the decision to exploit entrepreneurial opportunities (Shane & Venkataraman, 2000).

Access to resources has a significant direct, positive effects on opportunity recognition for entrepreneurs (Ozgen & Baron, 2007). Within resource-based theory, resources are what afford firms entrepreneurial advantage in the market. For example, social networks and forms of support are resources that provide information and access to opportunities (Chang, Memili, Chrisman, Kellermanns, & Chua, 2009; Huybrechts, Voordeckers, Lybaert, & Vandemaele, 2011; Ozgen & Baron, 2007). Further, beliefs about the value of resources are, in and of themselves, resources (Alvarez & Busenitz, 2001). Whereas one could claim that opportunity is a resource, one could also argue that resources are opportunities or that resources facilitate opportunity recognition and creation. Thus, the relationship between theories of opportunity recognition and resource-based theory is a recursive one. In light of all that has been said above, entrepreneurship can thus be defined as: “a process by which individuals – either on their own or
inside organizations – pursue opportunities without regard to the resources they currently control” (Stevenson & Jarillo, 1990, p. 23).

What drives social entrepreneurship, and distinguishes it from commercial entrepreneurship, is the need to address a social problem. There are a wide range of definitions of social entrepreneurship that span for-profit, nonprofit, and hybrid models; each integrating varying degrees of social value or objective. Underlying the diverse models of social entrepreneurship is the impetus to create social value in place of solely monetary profit (Austin, Stevenson, & Wei-Skillern, 2006; Bornstein & Davis, 2010). The organizational form of social entrepreneurship, therefore, should reflect what most effectively addresses the specific social problem. In this way, the “social enterprise” is not a legal entity and retains flexibility with regards to its structure, which enables it can take on various different formats. Social entrepreneurship blurs the boundaries between sectors (Bornstein & Davis, 2010). The definition of entrepreneurship can therefore be amended to presume that social entrepreneurship is a “process by which individuals – either on their own or inside organizations – pursue social opportunities without regard to the resources they currently control” (Stevenson & Jarillo, 1990, p. 23). This research and the larger project begin to explore how social entrepreneurship manifests in the disability sector. Certainly, defining social entrepreneurship as a process rather than simply a legal entity opens the possibility for inclusion of people with ID significantly. However, the use of the term “social entrepreneurship” as it is applied for and by people with disabilities challenge these theoretical distinctions.

2. Perspectives on disability

In the United States, people with disabilities have a long history of oppression and institutionalization that continues today. This is often because disability has been defined using
deficiency models, frequently referred to as the *medical model*, which posits that “disability” is a defect or problem within the individual that needs to either be fixed or eradicated (Carey, 2003; Oliver, 1996; Pfeiffer, 2002; Rioux & Bach, 1994). Disability studies scholars offer dissenting viewpoints to such an approach; chiefly among them the *social model* of disability. The social model holds that disability is not inherent in the person, but rather it is society’s inability to meet their needs that is disabling. The social model focuses on the systemic, socially-constructed barriers and restrictions that people with impairments face and thereby removes blame from the individual; transferring it to society. The social model of disability has proven politically effective because it provides a material and concrete solution for addressing discrimination by removing barriers to social and economic participation. The extent to which socio-cultural factors affect entrepreneurship has been understudied and merits critical attention (Thornton, Ribeiro-Soriano, & Urbano, 2011).

Critique of an economic approach to disability, one which measures value in terms of participation in the workforce, permeates theoretical discourse on the political economy and the position of people with disabilities in it. Frequently, such an approach does not appreciate mitigating factors affecting one’s ability to participate and the barriers to such participation. Marginalized and disenfranchised, people with disabilities are forced to occupy the peripheral spaces of mainstream employment. The literature on employment and disability is essentially bifurcated around the topic of ID. While literature addressing disability in general can be extended to include people with intellectual disabilities, it does not necessarily speak to the specific issues of that group. Conversely, it begs the question to what extent research specific to ID can be generalized to apply to people with disabilities. This phenomenon is further complexified by the existence of a hierarchy of impairment that recognizes the propensity of
people with disabilities to experience resistance to other impairment groups seen as competing for scarce allocations of resources or due to stigma (Deal, 2003). This is particularly salient to the topic of employment for people with ID in light of the observation that, “those ranked lowest in the hierarchy become even more vulnerable to the vagaries of social policy without the support of those who should be their comrades and defenders” (Deal, 2003, p. 907). Policy created to encourage entrepreneurship among people with disabilities will affect people with ID. However, it is not well understood to what extent or how that affect will manifest. It is therefore imperative that research on social entrepreneurship and disability be explicitly inclusive of ID.

It is common practice for “disability” to be used as a universal category. While it could be argued that doing so neglects to fully recognize the heterogeneity of the disability experience, from a Disability Studies approach, the term is politicized and becomes a strategic designation uniting individuals with diverse differences and common experiences of oppression (Fujiura & Rutkowski-Kmitta, 2001; Gill, 1999; Watson, 2002; Wilson & Lewiecki-Wilson, 2001). It is similarly socio-politically important to allow individuals to self-identify as having a disability. Indeed, parallels have be drawn with the sentiment expressed by Black American feminist writer Patricia Hill Collins:

By insisting on self definition, Black women question not only what has been said about African American women but the credibility and intentions of those possessing the power to define. When Black women define ourselves, we clearly reject the assumption that those in positions granting them the authority to interpret our reality are entitled to do so. (Watson, 2002, p. 512)

Subsequently, it becomes apparent that self-identification is not only a socio-political issue, but also a site of potential selection bias if the researcher is imputing a categorical label onto individuals who do not identify as such (Watson, 2002).
3. **Perspectives on intellectual disability**

Traditionally, disability has been approached from a positivist perspective, reliant upon a scientific process of classification and labeling of individuals inherent within the medical model (Hahn, 1993; Marks, 1999; Rapley, 2004; Siebers, 2001; Smith, 1999). ID can be seen as anathema to the medical model, because it cannot be observed objectively, measured, or “cured” (Siebers, 2001; St. Claire, 1993). Attempting to view ID as pathology places the focus on an individual’s limitations, comparing them to a standardized non-disabled norm that serves to enhance differences (Davis, 2006a; Siebers, 2001; Smith, 1999). Deficiency models, as defined herein, are not limited to the medical model and can be found throughout literature on education, employment, and citizenship (Barnes & Mercer, 2005; Carey, 2003, 2009; Gabel, 2005; Llewellyn & Hogan, 2000; Shakespeare, 1998).

Within the last half-century, a sociological approach to understanding intellectual disability has garnered a great deal of attention. This theory of the *social construction* of disability differs from the *social model* in that it posits that “reality” is socially constructed, created, and defined (Bogdan & Taylor, 1989; Rapley, 2004; Siebers, 2001; Smith, 1999). The conception of reality is seen as having many possible interpretations. For instance, in 1989 Bodgan and Taylor wrote a poignant article on the social construction of humanness through observing the relationship between people with severe ID and their nondisabled caregivers. The authors found that caregivers involved in accepting relationships where they attributed thinking to the other, often counter to professional opinion, permitted them to see the individual with ID as valued and loved human beings. Rather than allowing individuals with severe ID to be defined solely by their disability, the process of attributing thinking enabled caregivers to
construct a social place for this othered group whose personhood has been so questioned (Bogdan & Taylor, 1989).

Who is or is not considered [intellectually disabled] hinges on arbitrary and professionally controlled definitions and classification procedures. The construct of [intellectual disability] exists in the minds of those who label other persons, and not those so labeled. (Taylor, 1996, p. 4)

This reality is a function of institutional landscapes and, as a result, our understanding of it must consider the socio-political environment as well as the boundaries placed upon it. Whereas limitations of individuals with disabilities within deficiency models are viewed biologically and cognitively, in the social construction model these limitations are thought to be imposed by political and social forces corresponding to public attitudes (Hahn, 1993; Smith, 1999). Accordingly, the environmental restraints that predicate disability are the result of social attitudes of the non-disabled majority, differing materially from the social model of disability. Indeed, the social model has been heavily criticized for not engaging ID conceptually and thereby excluding individuals with ID from such scholarship (Chappell, 1998; McClimens, 2003; Rapley, 2004). While some British scholars have endeavored to bridge this gap by reconceiving a social theory of impairment (Chappell et al., 2001; Goodley, 2001, 2004; Goodley, Armstrong, Sutherland, & Laurie, 2003), social constructionism remains the prevailing standpoint among ID researchers in the U.S.

The multiplicity of labels for the concept of intellectual disability is epistemologically problematic (Goodey & Stainton, 2001; Rapley, 2004). Particularly given that to a large extent the meaning of intellectual disability and what it means to be a person with ID are so socially constructed (Bogdan & Taylor, 1989; Finlay & Lyons, 2005; Goodley, 2001; Goodley et al., 2003; Goodley & Roets, 2008; Rapley, 2004). Regardless, social and diagnostic categories are imposed to construct groups of people labeled as intellectually disabled and typically categorized
as having mild, moderate, or severe levels of impairment. The most enduring expression of this phenomenon relies upon an intellectual functioning quotient, an IQ score of approximately 70 or below (AAIDD, 2008).

The current accepted working definition of ID attempts to unify the perspectives of the medical model and social constructionism as ID is seen to be a “disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills” originating before the age of 18 (AAIDD, 2008; Schalock, Luckasson, & Shogren, 2007, p. 118; Wehmeyer et al., 2008, p. 312). Adaptive skill areas include communication, leisure, health and safety, self-care, home living, self-direction, functional academics, community use, and work (D. Dunn & Crouch, 2001; Wehmeyer et al., 2008). This widely accepted definition recognizes the importance of social factors in interpreting cognitive and biological functioning and asserts that the classification of an individual as intellectually disabled must take the context into consideration relative to one’s peers and culture. Moreover, one’s cultural and linguistic differences should be taken into account as well as their communication, sensory, motor, and behavioral factors recognizing that within individual limitations often coexist with strengths. The viewpoint is espoused that limitations must necessarily described in order to develop an effective individualized plan of needed supports; and the appropriate supports should be provided in an approach that improves the functioning of the individual with ID (AAIDD, 2008).

According to the University of Missouri’s 2001 Handbook of Disabilities, individuals with ID can also be classified in two complementary ways (D. Dunn & Crouch, 2001). The first considers mild impairment, accounting for 85% of the population, to indicate that with training these individuals can live and work independently. Moderate impairment applies to 13% of
individuals who are considered trainable for basic skills in selected vocational areas. Severe classification is reserved for the most profoundly affected 2% of the population of persons with ID and reflects an inability to care for one’s basic needs. An individual may also be classified according to the intensity of their support needs. For instance, intermittent support needs are those which are provided only as needed; most of the time an individual functions well on his own. Limited support needs are provided as needed but on a regular basis, which may later be transitioned out of. Extensive support needs are provided continuously and on a long-term basis, but only in one or two aspects of an individual’s life. Finally, pervasive support needs are provided long-term and continuously in several aspects of an individual’s life. This research will not attempt to define, diagnose, or impose a categorization of ID onto the participants. Rather, the participants in this research self-identified as having an intellectual disability.

4. **Social networks and forms of support**

There exists a considerable body of literature in both entrepreneurship theory, disability theory, and intellectual disability research that address the importance of social networks and forms of support, be they formal or informal. Several critical parallels can be drawn by integrating this information, which will then be used to inform and reify the question of intellectual disability and social entrepreneurship.

a. **In entrepreneurship literature**

The network approach to entrepreneurship is a prominent thread in entrepreneurship theory that draws upon the social capital metaphor and asserts that not only are social networks key in establishing new firms, but also that they are instrumental in achieving success (Bruderl & Preisendorfer, 1998). Most empirical research in the field uses a personal network perspective, rather than an organizational network perspective, because of its focus on
the individual businessperson while recognizing entrepreneurship as a social role. That is, entrepreneurs are not isolated, autonomous decision-makers, but rather their role is embedded in social, political, and cultural context (Bruderl & Preisendorfer, 1998).

The entrepreneur is guided by two factors: previous employment, which provides a model the entrepreneur can build upon; and social support, which increases the entrepreneur’s perceived options (Birley, 1985). For instance, support of family members influence how entrepreneurs acquire and manage resources, which are crucial for venture development (Chang et al., 2009). Entrepreneurship is a relational task in which social networking activities are inherent (Bruderl & Preisendorfer, 1998). Social networks help not only with procuring resources and financial possibilities, but also in gaining access to information, and in seeking advice and reassurance (Birley, 1985; Bruderl & Preisendorfer, 1998). Social networks differ in size, density, diversity, redundancy, and the strength/centrality of ties (Bruderl & Preisendorfer, 1998; Hoang & Antoncic, 2003). The structure of social networks are defined by direct and indirect ties between actors (Hoang & Antoncic, 2003).

Theoretical and empirical work on social networks in entrepreneurship research address three main constructs: the content of entrepreneurial relationships, the governance of these relationships, and the structure of these networks or pattern that emerges from relational ties (Hoang & Antoncic, 2003). As regards the governance of relationships, trust has been shown to be a critical factor in entrepreneurship as it affects the depth, richness, and overall quality of relational exchanges, particularly with regards to the exchange of information. Trust is associated with lower perceived risk and reliability regarding fulfillment of obligation. The expectation between partners built on mutual trust that actions will be both predictable and
mutually acceptable, results in reduced transaction costs such as those necessary in negotiations or to provide for oversight (Hoang & Antoncic, 2003).

_Social capital_ has become something that can be valued and created. Indeed, building social capital can be the key to success for a social entrepreneur who may have to be innovative because of structural differences or barriers (Bornstein & Davis, 2010). Social capital theory does not take into consideration groups “who, for various reasons, may not be able to develop their social capital in the community” (Pavey, 2006, p. 219). The same can be said for human capital. Capital theories bear resemblance to a deficit model of disability wherein the responsibility for developing capital is seen to lie within the individual rather than recognizing the role that society or societal institutions play. Further, by espousing an ideology of entrepreneurship the government could remove itself from responsibility. This perspective appears in criticism from disability scholars on the policy shift in the UK towards a “learning society” that emphasizes lifelong learning the development of entrepreneurial spirit (Pavey, 2006; Riddell, Baron, Stalker, & Wilkinson, 1997): Whereas social capital is theoretically supposed to bolster one’s human capital to help aspiring entrepreneurs overcome barriers (T. Bates, 1997), there has been concern that it may actually detract from it. For instance, focus on building social capital in education for individuals with ID might not emphasize the importance of developing skills needed to enhance one's employability, but could instead emphasize factors intended to promote their social networks and civic engagement (Riddell et al., 1997). Rather than participating in education to acquire marketable skills, critics are concerned that individuals would be engaging in education to enhance their own self-worth and quality of life. In pursuing education in this manner, one may be gaining social capital at the expense of human capital. As a result of this shift away from educational strategies promoting individualist economic
competitiveness towards promoting social cohesion, people with disabilities may find themselves further disadvantaged in a knowledge economy (Pavey, 2006). Such critical perspectives introduce an important caveat. However, it is equally important to acknowledge the role that social capital plays in addressing barriers to employment. Further, it has been suggested that capital theory has the potential to provide a framework which could disengage the focus of this discourse on employment and entrepreneurship from the examination of the individual as the center of the problem (Trainor, 2008).

Social capital has been described both as a glue, holding networks together, and as a lubricant, helping networks function better. Social capital is not an outcome, but rather a process involving both structural and relational aspects:

It is the process of creating a condition for the effective exchange of information and resources. It can only exist between people; accordingly it is a relational artifact which we can only observe as one or other of its dimensional manifestations. From this perspective social capital can be envisaged as a bridge-building process linking individuals, so that networks are a series of bridges that link numerous individuals. (Anderson & Jack, 2002, p. 207)

Envisioning social capital as a “bridge” is a familiar distinction made among social capital theorists. Putnam is noted for delineating between bridging and bonding capital (S. Baron, Field, & Schuller, 2000). Bonding capital refers to relationships formed between people who are similar, therefore creating strong ties that reinforce homogeneity and excluding those who do not conform to established norms. Conversely, bridging capital is formed among heterogeneous populations and, although resulting in weak ties, is believed to promote social inclusion and cohesion (S. Baron et al., 2000; Daly & Silver, 2008; Holt, 2008; Ward & Baker, 2005). However, the strength of weak ties should not be underestimated, particularly with regard to people with disabilities. Whereas weak ties have been criticized for generating alienation, they are actually fundamental to the creation of opportunity and integration into communities.
Moreover, because strong ties create local cohesion, they can actually lead social fragmentation (Granovetter, 1973).

Social networks play a role both in business founding and the start-up process (Birley, 1985; Bruderl & Preisendorfer, 1998). Entrepreneurs use networks to get ideas, gather information, and recognize opportunities (Hoang & Antoncic, 2003). During founding, network resources, networking activities, and network support are all factors that stimulate entrepreneurship and are heavily used in the establishment of new firms. During the process after founding, entrepreneurs whose social networks are broader and more diverse, and who therefore have more support, are found to be more successful (Bruderl & Preisendorfer, 1998). However, it is also possible that reliance upon social support networks may only be useful during the start-up phase (Yoon, 1991) and harmful over the long-term. This results in creating business that are less profitable and failure-prone (T. Bates, 1994) due to an over-reliance upon the vague and general social capital concept without taking into account how entrepreneurs make use of the opportunities these networks provide (Bruderl & Preisendorfer, 1998), or how their ability to make use of those opportunities are impeded by disabling barriers in our society.

Both formal and informal networks influence the nature of a firm and help the entrepreneur seek the optimal arrangement for their firm (Birley, 1985). Formal networks include local, state, and federal agencies such as banks, lawyers, the chamber of commerce, or the SBA. These formal networks are primarily reactive; many do not assess needs, but rather respond to specific requests. The drawback is that many of these sources do not have their own established networks and can deter the process by bureaucracy. Formal sources come into play when seeking financing, but the entrepreneur tends to rely upon their network of informal contacts as the primary source of support (Birley, 1985). Informal networks include family,
friends, and business contacts such as previous colleagues and employers (Birley, 1985). While informal networks may be less knowledgeable about available options and opportunities, they are more likely to listen and give advice. The main disadvantages are that information from these sources has the potential to replicate previous work experiences and they are unable to provide unbiased support. An efficient network “is one in which, no matter where the entrepreneur enters the network, his needs are diagnosed and he is passed round the system until he gathers the necessary information and advice” (Birley, 1985, p. 116). Therefore, an efficient system requires using both formal and informal forms of support where sources are clear on what services they offer. However, it bears noting that to this perspective depicts the entrepreneur as a passive product of their network rather than as an active agent, mobilizing the resources and opportunities available through their networks.

Despite being recognized as an essential element to both venture preparation and venture creation, the role of family social support (or capital) is not well understood or documented (Chang et al., 2009). Family networks increase success by providing resources and emotional support; giving access to unpaid family work, which can compensate for financial restrictions (Bruderl & Preisendorfer, 1998; Chang et al., 2009). Family strategies among immigrant entrepreneurs rely upon interpersonal bonds and common self-interests for sources of labor and financial resources in establishing and operating small businesses (Sanders & Nee, 1996). Indeed, family can be a resource for finding loyal employees that reduce entrepreneurs’ effort in needing to control new workers (Bruderl & Preisendorfer, 1998), particularly if family members have background and previous experience with entrepreneurship (Chang et al., 2009).

The argument that family firms outperform non-family firms has engendered considerable discussion around whether, from a resource-based view, family firms have a
competitive advantage due to unique factors in the way the family and the business interact (Huybrechts et al., 2011). It has been suggested that this is due to the unique combination of tangible and intangible resources, which involves seeing the family firm as more of a “lived experience” among interdependent actors (Huybrechts et al., 2011; M. H. Morris, Allen, Kuratko, & Brannon, 2010).

Entrepreneurs should not limit themselves to family as a source of social support (Chang et al., 2009), however. Using external sources of support lowers risks and elevates capabilities. Further, it can expand the network and capitalize on others’ expertise since these networks provide access to information, opportunities, and motivation (Chang et al., 2009). Often, entrepreneurs seek legitimacy, in an effort to reduce perceived risk, by associating with or applying for explicit certification from external individuals or organizational sources that are well-regarded (Hoang & Antoncic, 2003).

Waldinger and colleagues (2000) found that the revival of small business was largely due to an infusion of new ethnic owners. The initial market for immigrant entrepreneurs is usually within their own community because it has special needs and preferences best served by someone who shares those needs. A sense of ethnic solidarity contributes to the development of ethnic enclaves within which these businesses form (Sanders & Nee, 1987). However, staying within an ethnic market limits the potential for growth because it can only support a certain number of businesses; the communities are small, and ethnic populations are usually too impoverished to have sufficient buying power to sustain a lot of businesses well. Therefore these communities see proliferation of small business, over-competition, and high failure rates. Further, those businesses that do survive do not make strong returns. While the ethnic market can serve as an entry point in expansion to other markets, growth potential is dependent upon
access to customers beyond the ethnic community (Waldinger et al., 2000). This has interesting implications for social entrepreneurship among people with ID given the debate between segregated and integrated employment and the position of enclave work scenarios. Additionally, it bears consideration the extent to which service provider agencies or communities may act as an enclave environment, allowing for easier market entry but limiting potential for long-term growth and development of the business.

b. **In intellectual disability literature**

While little disability literature has focused on social capital (Condeluci, Ledbetter, Ortman, Fromknecht, & DeFries, 2008; Potts, 2005; Trainor, 2008; Widmer, Kempf-Constantin, Robert-Tissot, Lanzi, & Carminati, 2008), much attention has been paid to the importance of social support. For people with disabilities, social support has been shown to be important because of the role it plays in preventing health and mental health problems as well as improving overall quality of life (Pescosolido, 2001; WHO, 2011). This is especially true for people with intellectual disabilities (Bigby, 2008; Felce & Emerson, 2001; Lippold & Burns, 2009; S. M. Miller & Chan, 2008) because of the role that supported living plays in advancing deinstitutionalization towards community-integrated living (Bigby, 2008; Forrester-Jones et al., 2006; Kozma, Mansell, & Beadle-Brown, 2009) as well as the role that supported employment plays in achieving self-determination and social participation (Banks, Jahoda, Dagnan, Kemp, & Williams, 2010; Beyer, Brown, Akandi, & Rapley, 2010; Eisenman, 2007; Forrester-Jones, Jones, Heason, & DiTerlizzi, 2004; Jahoda et al., 2009; Jahoda, Kemp, Riddell, & Banks, 2008; Kilsby & Beyer, 2002; D. Mank, Cioffi, & Yovanoff, 2000; D. Mank, Cioffi, Yovanoff, & Taylor, 2003; Novak & Rogan, 2010; Trainor, 2008).
Support is a way to lessen the impact of barriers and promote equal access and opportunity for people with disabilities. The conceptualization of social support within disability literature recognizes both formal and informal sources of support. Formal support refers to service systems and the professionals that operate within them; whereas informal support refers to sources such as family, friends, neighbors, and co-workers, which embody an indispensable form of social support that people with disabilities draw upon in their pursuit of economic advancement (WHO, 2011). Informal support is based on personal ties rather than payment and has four main components: “emotional support, direct instrumental support, financial assistance, and management of relationships with formal organizations” (Bigby, 2008, p. 148). The role of Personal Assistants and Personal Support Workers straddle the line between formal and informal care work because while they are monetarily compensated for their work, they also tend to develop friendships and close relationships with clients (Kelly, 2010).

An overwhelming majority of people with disabilities require some form of support from informal carers (A. C. Hall & Kramer, 2009; Matthias & Benjamin, 2008; G. Parker, 1992; Rizzo, 2002). For example, in the U.S. over 75% of people with various disabilities receive care from unpaid informal carers (L. Thompson, 2004). For adults with developmental disabilities, over 75% live at home with their family (Braddock, Hemp, & Rizzolo, 2008). Informal family support therefore continues to play a significant role in the lives of people with disabilities. However, even despite strong ties to family and friends, people with disabilities may still be limited in their social capital. For example, people with ID engage less frequently in community activities, participate in fewer social activities, and have fewer personal social relationships (Felce & Emerson, 2001).
The social network is one of the key elements to understanding social support (Pescosolido, 2001; Potts, 2005). Further, these networks differ considerably in both size and composition for people with disabilities than for those without (Bigby, 2008; Eisenman, 2007; Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson, Emerson, Gregory et al., 2001; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). However, considerations about such socio-cultural differences have yet to be integrated with entrepreneurship research. Research has shown that the social networks of individuals with disabilities tend to be smaller and less diverse, especially for those with ID whose social networks are more restricted (Bigby, 2008; Eisenman, 2007; Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson, Emerson, Gregory et al., 2001; Verdonschot et al., 2009). For instance, the average network size for someone with ID, excluding staff, comprises two people; one of which is typically family or another person with ID (Robertson, Emerson, Gregory et al., 2001).

In a comparison of the social support networks of adults with intellectual versus physical disabilities, Lippold and Burns (2009) surmised that while community integration creates more opportunities for activities, it does not correspond with good social and emotional support – physical community presence is not, in and of itself, sufficient to achieve integration. This observation can be applied to the topic of integrated employment for people with disabilities to illustrate the importance of establishing workplace supports and strengthening social networks to create employment opportunities and build social capital (Carey, Potts, Bryen, & Shankar, 2004; Eisenman, 2007; Forrester-Jones et al., 2004; Potts, 2005; Rizzo, 2002; Trainor, 2008). Further, many people with disabilities lack the weak ties that are not connected to other people in their network (Condeluci et al., 2008). Balanced networks consisting of both weak and strong ties are
valuable for expanding a new venture beyond its initial startup (Uzzi, 1996), and people with disabilities may be at a disadvantage.

In exploring to what extent social networks influence the careers of young adults with ID, and to what extent differences in social networks for this group mediate employment opportunities more so than disability status or prior work experience, Eisenman (2007) found that while school and adult agency personnel provided an important source of career resources, the social networks of participants interviewed were dominated by family members and family activities. While family ties mean access to a strong source of information, support and extended career ties, individuals had few community acquaintances. Because of the lack of work experience, individuals with ID had few weak ties (Eisenman, 2007). It is interesting to consider how the responsibility for making informal ties often falls upon individuals in formal networks, particularly for middle-aged and older adults with ID who often do not have family support and are found to be “known by no one” in either their formal or informal networks (Bigby, 2008). For many individuals with ID, work serves as an important medium through which to develop social relationships (Chadsey & Beyer, 2001).

5. **Independence, interdependence and self-determination**

At its core, discourses on disability have a rhetoric of *independence*. The Disability Rights and Independent Living Movement in the U.S. drew upon an empowerment framework to counter societal misconceptions of people with disabilities that fueled discriminatory practices excluding people with disabilities from equal participation and thereby denied them certain rights (Charlton, 1998; Fleischer & Zames, 2001). Independence is a fundamental issue for people with disabilities because it refers not just to a need for self-reliance, but also to a need for *self-determination* – the ability to choose and control the ways in which
one lives (J. Morris, 1998; Reindal, 1999). There is a gross disparity between people with ID in the general population regarding the extent to which they control their own lives. It is for this reason that self-determination and choice are crucial to the study of contemporary issues in intellectual disability (Stancliffe, 2001). The relationship between self-determination and employment is a powerful one. Studies have found that people who live and work in integrated settings were more self-determined, more autonomous, made more choices, and reported being more satisfied with their job and lifestyle (Wehmeyer & Bolding, 2001).

Professionals, policymakers, and disability advocates are often divided over how independence is defined. It can carry vastly different implications that serve to either empower or disempower people with disabilities (J. Morris, 1998; Reindal, 1999). Often professionals and policymakers apply the same term that disability advocates do, but in reference to competing interests. In recent decades, disability scholars have critiqued conventional notions of independence in favor of an ideology of interdependence, employing a nuanced understanding of dependence and a valuing of interdependent social relationships (Lloyd, 2001; Priestley, 2001; Reindal, 1999; Walmsley, 1993; Wendell, 1996). This involves recognizing that dependence is not one end of a reductionist dichotomy. The relationship between independence and dependence is more complex and the two are not necessarily mutually exclusive. For instance, while some conservatives may perceive that people with disabilities who use entitlements are dependent upon government supports, these services are actually what allow people with disabilities to be independent, or rather, self-determined.

Having the freedom and support to recognize choices and make decisions is an essential component in achieving community integration and social participation for people with ID (Robertson, Emerson, Hatton et al., 2001). In a systematic review of literature on the topic of
self-rated participation for adults and adolescents with mild ID, researchers found self-determination to be one of the most frequently occurring factors of participation; definitionally including autonomy, independence, self empowerment, and decision making (Arvidsson, Granlund, & Thyberg, 2008). However, best practices concerning self-determination are debated and raise issues around the topics of support in decision-making and the viability of choice. Increasing attention to the topic of self-determination in the last decade has resulted in efforts to promote skill building, to change how adult services are funded, and to allocate resources in an effort to increase consumer control and direction (Wehmeyer & Bolding, 2001). However, the intersection of employment and self-determination is under-researched and needs further investigation. Care should be taken not to conflate self-determination with independence (Wehmeyer & Bolding, 2001). While self-determination can certainly foster independence, it should not necessarily be taken to mean working independently. When the terms are conflated people mistakenly think that self-determination necessarily leads to independence we undermine the value of interdependence (Reindal, 1999).

D. **Theoretical Framework**

The purpose of this research is to reify “success” for individuals with ID involved in social entrepreneurial ventures. As outlined in the conceptual framework, this process involves the integration of two distinct theoretical disciplines, Disability Studies and social entrepreneurship, while centering and contextualizing it within research on ID. Situating this topic within citizenship theory (Figure 2) provides a useful way of conceiving of participation, particularly if we think of citizenship as group membership, because it allows for engagement with discourse on rights and social justice. Social entrepreneurship can be a powerful expression of citizenship.
Accordingly, a disability critique of citizenship, and the ways in which it has been used to marginalize and disenfranchise people with I/DD, will lead to a better understanding of how policymakers and practitioners can promote and support innovative strategies such as social entrepreneurship as vehicles for empowerment and self-determination. From a Disability Studies perspective, theories of disability draw upon the social model and interdependence literature to strengthen complementary constructs within intellectual disability literature, which include social constructionism, self-determination, and support. This will be incorporated with theories of citizenship to unpack the notion of participation at each level of group membership.

Employment is presented as a level of group membership that speaks to a sense of economic citizenship, and social entrepreneurship has been promoted as an opportunity for social mobility towards achieving membership in this capacity. Social entrepreneurship literature that
is informed by entrepreneurship theory will be used to unpack the phenomenon of participation in social entrepreneurship for people with ID. Drawing upon various disciplinary backgrounds towards the three foci of motivation, management, and outcomes, entrepreneurship theory contributes to our understanding of social entrepreneurship as encompassing opportunity-recognition and resource-based theory as well as the centering of the social value proposition. This theoretical framework provides the tools and constructs necessary for the reification of “success” as it applies to individuals with ID participating in social entrepreneurial ventures by applying an understanding of participation that takes into consideration themes of self-determination, support, and interdependence.

1. **Situating within citizenship theory**

Often only thought of in terms of legal status and civic engagement, theories of citizenship pervade every discussion on difference and discrimination. It is a body of literature infused with the language of rights, membership, and equality (Lister, 1997). Citizenship refers to more than simply one’s relationship to a nation-state. It has grown to encompass our relationship to others, to society, and to ourselves. Citizenship has become a desirable activity, the expression of shared identity (Kymlicka & Norman, 1994; Meekosha & Dowse, 1997), and the very claiming of citizenship can itself be a powerful social act (Lister, 1997, 2007).

An understanding of citizenship plays a pivotal role in informing discussion on the participation of marginalized populations in society. Yet, until recently, the intersection of intellectual disability and citizenship has received little attention. The year 2009 saw the publishing of two thought-provoking and complementary works in this area by Allison Carey and Leanne Dowse. Carey’s book explores how U.S. citizenship developed out of liberalism in the twentieth century, resulting in the exclusion of people with ID from countless areas of social
life (2009). Whereas, in her article, Dowse begins to explore how modern citizenship has been shaped by the ideological shift towards neoliberalism (2009). She begins to delve into the challenges posed for people with ID in the twenty-first century. A comparison of the two reveals that while Carey provides a wonderful historical overview, and Dowse identifies several avenues demanding future attention, both stop short of engaging with citizenship on a theoretical level in favor of the material.

By situating the current research within citizenship theory, a reading that incorporates these points regarding liberalism and neoliberalism opens the dialogue to questioning the public/private divide in a way that allows us to engage with feminist thought on interdependence as well as the policy implications of public-private partnerships – presenting both theoretical and practical opportunities for the contribution of this research. Further, two of the main debates in citizenship theory, between active/passive citizenship and between universal/differentiated citizenship, can be used as tools in reifying the citizenship of individuals with ID as it pertains to participation in social entrepreneurship.

a. **What (exactly) is citizenship?**

The way we think of citizenship in the United States refers to an ideal of liberal citizenship, which emphasizes a sense of individualism (Turner, 2006). The traditional and enduring definition, as denoted by T.H. Marshall, is that citizenship is “a matter of ensuring that everyone is treated as a full and equal member of society. And the way to ensure this sense of membership is through according people an increasing number of citizenship rights” (Kymlicka & Norman, 1994, p. 534). In Marshall’s estimation, full citizenship requires the recognition of three kinds of rights: civil, political, and social; these rights developing in historical shifts over the past three centuries (Marshall, 2006).
The eighteenth century saw an expansion of civil rights, those rights necessary for individual freedoms such as liberty of the person, freedom of speech, the right to own property and conclude valid contracts, and the right to justice. Political rights followed in the nineteenth century, granting citizens the right to participate in the exercise of political power. It was upon the foundation of civil and political rights which social rights were cultivated in the twentieth century:

By the social element I mean the whole range, from the right to a modicum of economic welfare and security to the right to share to the full in the social heritage and to live the life of a civilized being according to the standards prevailing in the society. (Marshall, 2006, p. 30)

Shifting priorities to social rights were reflected in the growth of social welfare policies both in Britain and the U.S. Liberal citizenship is often referred to as passive citizenship because membership becomes an entitlement and participation is not contingent upon obligation. Meaning that one doesn’t have to do anything to be a citizen, they simply are citizens; thereby enabling the marginalized to enter the mainstream under the provision and protection of these rights (Kymlicka & Norman, 1994). Social rights therefore, theoretically, enable disadvantaged groups to exercise their civil and political rights effectively and are fundamental to the promotion of individual autonomy and self-determination (Lister, 1997, 2007). However, liberal citizenship does not recognize the structural and attitudinal barriers that people with disabilities encounter or the ways in which a disabling society limit their citizenship and ability to participate as a full and equal member (Barton, 1993; J. Morris, 2005; S. Parker, 2007).

i. **Active versus passive citizenship**

One of the foremost debates in citizenship theory is between active versus passive citizenship. Whereas passive citizenship developed out of liberalism, active citizenship developed out of civic republicanism, which promotes the idea that citizenship is
more than just a legal status, it is an activity and a moral responsibility (Oldfield, 1998).

Members of society are considered to have a responsibility, not just to themselves, but also to the communities within which they live. It is believed that only through coming together as a collective interest that inequalities can be overcome (Lister, 1997; Oldfield, 1998). The role of the social entrepreneurs as a “change maker” holds interesting implications regarding the ideal of active citizenship and the social role of the entrepreneur (Bornstein & Davis, 2010; De Clercq & Honig, 2009; Dees, 2001).

There is a radical form of active citizenship that has been adopted by some feminists as a vehicle to bring together people who are disadvantaged to empower them to improve their own quality of life. However, active citizenship poses a dilemma where feminism is concerned because, while it could be a path to liberation, it is also an inherently problematic ideal. In every society there will be a group of individuals who are passive – too disempowered or alienated to participate. Rather than transcending group difference, civic republicanism may serve to reinforce the exclusion of marginalized groups (Lister, 1997), and people with disabilities in particular (S. Parker, 2007).

Yeung and colleagues (2008) conducted interviews with young adults who had cerebral palsy to explore how they chose to define citizenship for themselves in terms of both contribution and inclusion. They found that to be a citizen meant not only identifying with and having a sense of belonging within a community, but also having respect for themselves and others, helping others, and giving something back to society. For these participants, being a citizen meant the recognition of one's intrinsic worth as a valuable contributing member of the community as well as being seen as a full member of society. In developing a feminist synthesis of rights and participatory approaches to citizenship, Ruth Lister offers that, “To act as a citizen
involves filling the full potential of the status. Those who do not fulfill that potential do not cease to be citizens” (Lister, 1997, p. 36).

ii. **Universal versus differentiated citizenship**

Within feminist discourse on citizenship there is a debate between *universal* versus *differentiated* citizenship that also finds itself replicated in approaches to disability policy. Whereas universal citizenship hopes to transcend difference and afford everyone the same status in society by recognizing a common humanity (Lister, 2007; Young, 1989); differentiated citizenship asserts that citizens participate not just as individuals, but as members of a group and rights depend partly on group membership (Young, 1989). Universal citizenship has engendered criticism from cultural pluralists who argue that universalism does not transcend difference so much as neglect it as common rights cannot accommodate for the special needs of minority groups (Kymlicka & Norman, 1994). Given that inclusive forms of citizenship necessarily produce exclusion (Lister, 2007), ignoring the differences between groups could serve to “enhance the domination of groups which are already dominant, and would silence the marginal and oppressed groups” (Yuval-Davis, 1997, pp. 17-18). Iris Marion Young argues that it is only through differentiated citizenship, then, that the rights of excluded groups with distinctive needs can be met. However, critics of this view contend that in differentiated citizenship there is no cohesion or social solidarity. Further, by focusing on difference we could create a “politics of grievance” whereby group leaders would spend their energy and resources establishing disadvantage so that they would be able to claim group rights (Kymlicka & Norman, 1994). This debate resonates within the disability community through discussions regarding universal human rights and differentiated “special” rights. For example, the question of whether
students with disabilities would best be served via mainstreaming or special education is a question of universal versus differentiated citizenship.

2. **Challenges to citizenship for people with intellectual disabilities**

In her book Carey (2009) raises several interesting points, chiefly among them that liberal political theory assumes citizens to be rational, independent agents and excludes those not meeting these standards. Therefore, within liberalism, intellectual disability is used as exclusion criteria from the realization of citizenship. Inclusion necessitates addressing the assumptions of liberalism and redefining the roles of competence, independence, and equality in determining the relationship between people with ID and rights. In short, it calls for a valuing of interdependence. Carey’s observation that liberalism has stressed negative liberties and the provision of autonomy, while disability activists have fought to enforce positive rights requiring individuals and institutions to engage in action is interesting. She argues that both positive rights and negative liberties are constrained by social institutions and relational patterns.

Recognizing the connection between liberalism and the marginalization and exclusion of people with ID is a useful tool in exploring complex phenomena, such as participation in entrepreneurship, because it frames our understanding of that participation and the challenges posed to it by the assumptions Carey denotes. Many of the challenges that will be encountered in neoliberalism are similarly the result of this liberalist ideology; exacerbated by its latest recapitulation in neoliberalism. Neoliberalism has resulted in a preoccupation with market forces. It re-categorizes formerly public issues into the private domain and, in doing so, complexifies the public/private divide and obfuscates the role and responsibility of the state. Consequently, the role of government has shifted from one of social insurance to one that
promotes and facilitates the activities of autonomous individuals (Dowse, 2009) and prompts us to question, what (exactly) is neoliberal citizenship and who are neoliberal citizens?

The concern with the increasing deregulation encouraged by neoliberalism and the increasing number of public-private partnerships forming is that public services will become subject to a free market ideology where competition is not necessarily in the best interest of the consumer and where the needs of disadvantaged populations could potentially become lost to the capitalistic impulse should adequate provisions (such as oversight and regulation) not be put into place. While deregulation and less government involvement could theoretically mean more freedom and increased self-determination, in practice it could result in less choice because the state is not providing for equal opportunity due to a lower degree of accountability in the private sector and a greater degree of freedom on the part of those organizations that can take advantage of consumers who are dependent upon services. If so, then the application of market principles to the privatization of services for individuals with ID appears to have a “paradoxical effect of limiting rather than promoting choice” (Dowse, 2009, p. 579). This argument is challenges the justification for turning to social entrepreneurship as a viable employment alternative for people with disabilities. Is it indeed an alternative that would allow for economic self sufficiency, independence and social inclusion (Blanck, 2000; Blanck & Schartz, 2001), or is it a vehicle being used to remove the government of responsibility in providing for social welfare (Wehman, Griffin, & Hammis, 2003)?

a. Culture of risk

We are a culture of risk and neoliberalism reinforces this ideology. Fueled by ableist notions, employment is inevitably a question of risk when it comes to people with disabilities in general (Titchkosky, 2003) and ID in particular (Dowse, 2009). This may manifest
in the form of employers perceptions (R. L. Morgan & Alexander, 2005), parents perceptions (Almack, Clegg, & Murphy, 2009), staff perceptions (M. C. Dunn, Clare, & Holland, 2010; Vallenga, Grypdonck, Tan, Lendemeijer, & Boon, 2006), or the perceptions of people with ID themselves (Jahoda et al., 2009; Jahoda et al., 2008). It is unclear what role risk plays in social entrepreneurship for people with ID; possibly acting as both a barrier and a motivating factor. For social entrepreneurs in general, uncertainty and risk of failure is a necessary part of innovation occurring throughout a continuous process of learning and growth (Dees, 2001).

The dignity of risk, a concept developed by Perske (1972), contends that the denial of exposure to normal risks undermines the personal development and sense of human dignity of people with ID. A meaningful life must contain a “reasonable amount of risk.” True danger lie in overprotection that will limit a person's individuality and growth potential, endanger their human dignity, and keep them from experiencing the risks in life necessary for human growth and development – in effect disabling them and limiting opportunities for social participation.

Concerns about risk to the welfare of a disabled person are closely tied up with assumptions about an individual's capacity to make decisions. The tendency to see disabled people as uniquely vulnerable means that, even when service providers talk of 'empowerment', concerns about safety and liability can get in the way. For example, much research on services for people with learning disabilities finds that, even within services which have stated philosophies concerning the empowerment of people with learning disabilities, concerns about safety override the desire to empower service users. (J. Morris, 2004, p. 431)

Risk is an important element of everyday life and it is important to move beyond seeing risk as a hazard assessment, as failure to take care of one’s self, or as failure to provide care (Almack et al., 2009). Viewing risk through the lens of social entrepreneurship makes possible the deconstruction of such ableist notions of risk that denote failure, rather than seeing both risk and failure as integral parts of “success” (Sarasvathy, 2001). Additionally, if people with ID are already unemployed, underemployed, and experience glaring income disparities; the only
apparent risk social entrepreneurship poses is in perpetuating existing models of oppression. However, in order to do so it would have to diverge theoretically so drastically as not to be recognizable as social entrepreneurship but rather would reflect a bastardization of the concept. This gets to the heart of this dissertation research and the importance underlying the need to understand what “success” means for social entrepreneurs with ID.

3. **Citizenship as group membership**

The key elements of citizenship are membership of a community, rights and obligations attendant to that membership, and equality (Lister, 1997). As such, citizenship is relational. It is important to think about citizenship as group membership, particularly for people with ID. This is not only because of the emphasis on community integration and social participation, but also because their roles and experiences have been so often been relegated to the private domain – hidden away from society. Often people with ID aren’t seen as full, public citizens; largely because of how ID has been used as the benchmark to exclude people from citizenship. However, people do not just have membership in one community. Rather, we have intersecting and overlapping memberships in multiple communities (Robinson & Tajfel, 1996). By thinking of citizenship as group membership it provides a tool for considering how citizenship may be different in each of these groups for each of these different memberships. To add to Carey’s earlier observations (2009), it is precisely because rights and citizenship are relational and context dependent that the extent to which positive rights and negative liberties are constrained by social factors varies at each level of group membership.

In general communities are self-chosen, based more on similarities than differences. However, the process of deinstitutionalization constructed communities based on differences. “Community” continues to be defined for people with ID by service providers and policy makers
(Cummins & Lau, 2003; Todd, 2000); speaking to the phenomenon of people with disabilities having to live “in but not of” their communities and speaking to the assimilative nature of participation (Milner & Kelly, 2009; Todd, 2000). Accordingly, participation is a political act (Beart, Hardy, & Buchan, 2004; Milner & Kelly, 2009). While participation occurs in a public “community,” a sense of belongingness and support may be found in private spaces, often among others with ID (Beart et al., 2004; Cummins & Lau, 2003; E. Hall, 2004; Milner & Kelly, 2009; Todd, 2000). While some scholars, such as Cummins and Lau, are critical of whether integration has become a forced choice rather than the realization of autonomous choice, for many individuals with ID a truly informed choice is already limited by social institutions given the lack of resources for alternatives to segregated work and nonwork options (Butterworth & Boeltzig, 2008). Perhaps, as has been suggested, it is not where, but rather how people participate that really matters (Milner & Kelly, 2009). In this vein, social entrepreneurship should be considered as just that, another option; an opportunity for social and economic participation that can occur either on one’s own or inside organizations.

Many theorists, most notably among them Iris Marion Young, have acknowledged that citizenship and group membership are closely interrelated concepts. However, it is by conceiving of citizenship as group membership that we can more meaningfully engage with the construct if intellectual disability, which has been remarkably neglected by citizenship theorists. It is important to recognize that citizenship issues occur at every level of group membership. Wherever group membership, or lack thereof, can be discerned there are questions of equality as well as of the rights and obligations attendant.

Levels of group membership are important because they set the correct scope concerning the active/passive and universal/differentiated debates. Further, doing so recognizes that these
do not present mutually exclusive positions. For instance, an individual could argue for universal rights on one issue, believing that position to be most appropriate or strategically effective, whereas they could maintain a position of differentiated rights on another issue – the level of group membership appertaining directly to the issue at hand.

Group memberships span both public and private spheres and can range from macrosocial to microsocial in scale (Robinson & Tajfel, 1996). Levels of group membership can range from something as broad and encompassing as human citizenship, to something as personal and intimate as sexual citizenship. Debates around these topics are abundant, but many have yet to be framed in terms of citizenship. Consider that with regards to human citizenship, the United Nations Convention on the Rights of Persons with Disabilities used a human rights approach that denoted a common citizenship within the human community (UN CRPD, 2010). Bodgan and Taylor (1989) were also speaking to a notion of human citizenship in their work on the social construction of humanness for people with severe ID and the role of family therein. A divergent perspective would be that of Peter Singer, who argues not necessarily for human citizenship, but rather animal citizenship wherein people with ID are again excluded (Carlson, 2010a; McBryde Johnson, 2010).

Other possible types of citizenship include intellectual citizenship, often discussed in relation to university level education and school of thought, but can certainly be expanded upon given recent emphasis on post-secondary education for people with ID and regarding the numerous questions of competency that arise with this group. Considering citizenship within and between the disability community/ies illustrates how the key element of equality is also an element of hierarchy and privilege. Familial citizenship refers not only to one’s role within the family as a contributing member, but also regarding the family as an acting citizen-body (a
Thinking of citizenship as group membership provides us with a valuable tool for how we conceptualize ID in approaching research, policy, and practice. This is particularly useful for interdisciplinary discourse on ID as it can help to improve communication between disciplines by enabling scholars to set the correct scope and provide better context within which to have critical discussions. It is essential that policy be informed by citizenship theory; otherwise, we run the risk of creating policy that limits some rights in the name of protecting others. Framing research such as this in terms of citizenship will help in minimizing misinterpretation.

E. Perspectives on Employment and Disability

An integral factor in social and economic participation, the right to work has been recognized as a fundamental human right. Employment refers to paid compensation for one’s work. Personal reasons that individuals with ID reported for wanting to work include earning money, productivity, the admiration of others, and the quality of social relations (Timmons, Hall, Bose, Wolfe, & Winsor, 2011). The UN CRPD highlights the importance of work and employment to the lives of people with disabilities and the right to work on an equal basis with others, “this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities” (UN CRPD, 2010, p. 17). Further, Article 27 of the convention states that towards this end, policy should promote opportunities for self-employment and entrepreneurship. Yet there exist glaring employment disparities between people with
disabilities and the general population that are often the result of social and environmental barriers. This gap becomes amplified for the ID community.

1. **Employment disparities**

Inequity in rates of employment for people with disabilities is unquestionable. During periods of economic uncertainty, unemployment is an issue weighing on the national conscience. While the economic downturn has affected everyone, it poses a unique challenge to a population already evidencing glaring employment disparities. The U.S. Department of Labor Economic Situation report for April 2011 (Bureau of Labor Statistics, 2011) shows that for people aged 16 to 64, 34.5% of people with disabilities participate in the labor market, compared with 76.4% of people without disabilities. When in the labor market, people with disabilities have a higher unemployment rate (16.2% to 8.6%). Research has demonstrated that low rates of labor market participation by people with disabilities affect the overall economy – with unemployment of people with disabilities contributing to an annual loss of between 1.37 and 1.95 billion U.S. dollars (Metts, 2000). Disability visibility and work experience are the most likely predictors of current work-status. People with invisible disabilities are 16 times more likely to be employed than people with visible disabilities (Martz, 2003). Moreover many qualified persons with disabilities continue to be directed to sheltered and non-integrated jobs, which do not allow for economic self sufficiency, independence, and social inclusion (Blanck, 2000; Blanck & Schartz, 2001).

Of those individuals with disabilities who are employed, few hold full-time jobs and considerably fewer compared with the nondisabled population (Blanck et al., 2000). Currently, only 21% of all working-aged people with disabilities are employed full- or part-time compared to 59% in the general population. Of those unemployed, 73% reported their disability was one of
the causal factors, 56% reported it was because they were unable to find a job, 37% reported it was the result of being unable to get accommodations in their workplace, and 23% reported that they fear losing their federal health benefits if they get a job (National Organization on Disability, 2010).

Both underemployment and subemployment are also significant problems in the disability community as many people with disabilities who are willing and able to work remain underemployed (National Organization on Disability, 2010), have lower salaries and lower levels of education (Blanck et al., 2000). Underemployment refers to “an involuntary employment condition where workers are in jobs, either part-time or full-time, in which their skills, including formal and work experience, training, are technically underutilized and thus undervalued relative to those other individuals of similar ability who have made equivalent investments in skill development” (Glyde, Davis, & King, 1977). There are two kinds of underemployment: intraskill and interskill. The former indicates an individual who is less able to utilize their skills than the average person, of equivalent ability, also endowed with those skills. The latter indicates an individual that has difficulty utilizing the skill because it is not as marketable.

Subemployment may be used to refer to people who are either not working and not actively seeking work because they do not believe they can obtain it, to people who are working part-time but desire full-time jobs, and to people who work full-time but at an income that is inadequate to provide financial support (Glyde et al., 1977). Often, the distinction between underemployment and subemployment is overlooked, but both are critical to understanding the problem of employment for people with disabilities and ID. Due to institutional, environmental, and attitudinal barriers, people with disabilities often encounter difficulty finding work. When they do find work they may experience conditions of subemployment, which fail to pay a living
wage. Even in subemployment scenarios there are aspects of underemployment wherein jobs do not match skills.

An analysis of occupational characteristics of workers with disabilities using a national dataset, the 2006 American Community Survey (ACS), found that employment disparities for people with disabilities effected not only earnings and employment levels, but also their occupational roles (Kaye, 2009). Even after controlling for educational level, employees with disabilities were disproportionately overrepresented in entry-level, unskilled, highly physical, and more hazardous occupations. These types of positions tend to have lower wages and greater risk of job loss or layoff. Correspondingly, people with disabilities were underrepresented in occupations that required proficiency in information, communication, and supervisory skills. These types of positions are associated with higher earnings and more job security (Kaye, 2009). Overall, underemployment results in lower wages and less job security and stability. Accordingly, its’ impact on the worker is palpable. Over time, being in a job that does not match one’s skills or work preferences can take a toll. Eventually, one becomes bored, unmotivated, and may lose their job (Kilsby & Beyer, 2002). In this vein, entrepreneurship has become a seductive policy prospect because of the promise for job creation that it holds (Blanck et al., 2000).

Job matching is one strategy that has emerged to address the problem of underemployment for people with ID (Kilsby & Beyer, 2002). This process involves the individual with ID matching their interests and abilities to available jobs in the community rather than choosing from available jobs based on whether or not they have those specific job skills (Kilsby & Beyer, 2002). Often this process is facilitated by employment service agencies and caregivers. The underlying premise is that ultimately interest and ability are more critical to
employment success than job skills because they will be more motivated and self-determined. However, this does not account for the people with ID entering employment for the first time who are often unaware of the employment options available and may not have the information or experience necessary to gauge their interests and abilities. One possible way to approach this dilemma is through job tasting: a short, unpaid, time-limited work experience that allows people to sample various workplaces and cultures. While this has been shown to be effective in supported employment, it may be limited in its applicability to self-employment and entrepreneurship. There is a start-up and creation phase to business development that may not be possible to replicate in a brief, time-limited simulation. Job matching, however, holds much potential. Consider the alternative of creating jobs based on one’s interests and abilities rather than matching skills to available jobs. The potential for job creation has been lauded as one of the benefits of entrepreneurship, not solely for people with disabilities (Blanck et al., 2000) but in relation to the general population as regards the health of the economy (Swedberg, 2000). While this potential for job creation is very likely a motivating factor in the promotion of social entrepreneurship for people with ID, it is unclear whether the justification is consistent with entrepreneurship theory. Rather, are people with ID encouraged to pursue social entrepreneurship for the same reasons as people with and without disabilities in general? Exploring the motivations of people with ID who are involved in social entrepreneurship will contribute to our understanding of the intersection of entrepreneurship theory and disability theory in a way that will concomitantly inform theoretical and practical ID employment literature.
2. **Competitive employment**

A common assumption is that full-time employment for people with disabilities is gainful when often it is not. Obtaining and maintaining employment, the two primary objectives of VR programs (Moore, Harley, Gamble, & Hasazi, 2004), are only part of the problem. People with disabilities need to be able to compete in the labor market. By recognizing employment as a right, people with disabilities should be entitled to protection from discrimination contributing to unemployment, underemployment, and subemployment. To this end, antidiscrimination legislation, such as the Americans with Disabilities Act (ADA), make it possible for individuals to pursue *competitive employment* (Blanck, 2000; Blanck & Braddock, 1998; Ozawa & Yeo, 2006). Sometimes referred to as mainstreaming or integrated employment, competitive employment involves working in the local labor market wherein an employee is hired, supervised, and paid directly by the business. Importantly, in competitive employment, employees receive the wages and benefits that are commensurate with non-disabled co-workers (Wehman, Revell, & Brooke, 2003). Since the passage of the ADA, more people with disabilities are choosing to pursue small business and self-employment opportunities (Blanck et al., 2000).

Title I of the ADA prohibits employers from discriminating against people with disabilities and requires that *reasonable accommodations* be provided, so long as such accommodations do not cause undue hardship for the employer (Bruyère, 2000). In 2008, the Supreme Court passed the ADA Amendments Act (ADAAA), which expanded the definition to include work as a major life activity (EEOC, 2004, 2010). However, the ADAAA has two significant limitations. First, it is primarily a reactive measure, enforced after a discriminatory act has already occurred. Second, ADA legislation is limited to conventional employer-
employee work arrangements (P. S. Miller, 1999). It is unclear whether self-employment or entrepreneurship would or even should be covered under the ADA. What kind of antidiscrimination legislation would protect this group? This question is pertinent because the intersection of entrepreneurship with the concept of competitive employment modifies the meaning of “competitive.” Instead of employees with disabilities competing with employees without disabilities, the issue becomes one of ensuring that business-owners with disabilities can compete in the economy, can be financially viable, and can have the same opportunities as other business-owners to participate in the marketplace.

3. **Gainful employment**

In 2007, during a time where the poverty rate in the U.S. was at 10% in the general population, 24.9% of adults with disabilities living in the community lived in poverty. For individuals with “mental disabilities” this rate had reached a startling 31.2% (Stats RRTC, 2010). That is, before the economy entered recession every one in four individuals with a disability and almost every one in three with a “mental disability” were living in poverty. Frequently this was due to the inability to find work that paid a living wage let alone provide *gainful employment*.

There is no set definition for gainful employment. Rather, it is left open to legal interpretation. However, Substantial Gainful Activity (SGA) is defined by the Social Security Administration (SSA) as someone who earns more than a set monthly amount, which is a figure determined by the SSA based on the net of impairment-related work expenses and the nature of a person’s disability. If an individual engages in SGA then they are disqualified from receiving social security income (SSI/SSDI) since “disability” is defined in the law as inability to
participate in substantial gainful activity (National Council on Disability, 2005). Currently, the SGA for non-blind individuals is set at $1,000 a month (Social Security Administration, 2010).

The economic resources of people with ID are very limited; even after adding earnings and benefits from income support programs. While the majority of individuals with intellectual and developmental disabilities (I/DD) remain unemployed, most of those who are employed report incomes either at or below the poverty level (Yamaki & Fujiura, 2002). In 2002, a national population-based study of people living in the community showed that 27.6% of adults with developmental disabilities were employed, compared with 75.1% of the general population; only 16% of these have full-time employment compared with 61% for the general population (Yamaki & Fujiura, 2002, p. 136). The majority of these jobs were in service occupations or labor jobs. For those individuals with I/DD who reported receiving earnings, their earned income was significantly lower than the general population with more than half earning less than $1,000 per month. It is interesting to note that more than half of people with developmental disabilities used income support programs, compared with only 7% for the general population. The mean earned income for individuals with mental disabilities was $1,298 per month compared to a mean earned income for the general population of $2,206 per month. One factor that should be taken into consideration is that a disproportionate number of individuals in this sample reported no income at all, which drastically skewed the distribution of income.

One possible explanation for this phenomenon may be found in the Fair Labor Standards Act (U.S. Department of Labor, 2010). According to this Act, as long as employers follow certain procedures they are allowed to pay workers with disabilities less than minimum wage. A Government Accountability Office (GAO) study found that of the 424,000 people earning subminimum wage, 74% of them were workers with I/DD (ARC, 2010). Theoretically, by
allowing employers to reduce the wage it will act as an incentive to hire and train people with more severe disabilities, who have behavioral difficulties, or who have fewer job skills. However, sheltered workshops for people with ID have been notorious for exploiting this Act to violate federal labor laws (Walling & Turner, 2010). In light of this information consider the following question; by pursuing social entrepreneurship for people with ID, what is there to lose? If the purpose of employment for people with ID is not necessarily to achieve financial self-sufficiency but rather to engage those with more severe disabilities to be productive and to teach job skills, then the very act of developing a social enterprise would accomplish the same goal but is created to meet the interests, needs, and skills of the individual. Further, social entrepreneurship holds a potential for creating a profit, both of monetary and social value, for the individual with disabilities directly that is lacking in many other employment options.

4. **Meaningful employment**

For people with ID, working in competitive employment resulted in feeling as though they were living a more purposeful life and increased their feelings of social status and self-worth. However, over time they reported fewer social opportunities beyond the workplace and anxiety about competence and being able to meet employer's expectations and demands (Jahoda et al., 2009). It is crucial that work be *meaningful*; speaking to what was mentioned earlier about matching jobs to interests and abilities. Most people with disabilities desire meaningful work and to be productive members of society. Additionally, productive engagement has been shown to contribute positively to overall health, mental health, self-esteem, and act as a buffer against stressful life events (Lysaght, Ouellette-Kuntz, & Morrison, 2009b).

In one study, Lysaght and colleagues (2009b) interviewed several young adults with ID engaged in work, volunteer opportunities, and personal projects. The research explored the
meaning of productivity, facilitators and barriers to achieving productivity, and the satisfaction people had with the roles they held. For many of those interviewed, work meant social recognition, it meant a connection to others and the world, and it meant pride and satisfaction. Despite finding little difference between people who were paid and those who volunteered, the study reported that money was the main reason most people worked. Money was a very personal factor that held instrumental value and signified the ability to support oneself or to have the financial freedom to buy “extras” that would not otherwise be affordable. For some study participants, payment legitimated their worth and contribution, thereby elevating their self-worth and feelings about their place in society. When asked the question, “Why do you work?” the most frequent responses noted that participants did not have anything else to do and work in order to not get bored. When asked about their work, many people reported having few options and little expectation things would change. These findings indicate an element of poor job matching and poor mobility. Regarding volunteer workers, most study participants stated that they would prefer to be paid. These individuals saw volunteering as a stepping stone towards paid employment and a way to gain skills that might later be used in seeking employment. However, they also saw it as a way to be productive without feeling as though they might lose their disability benefit eligibility (Lysaght et al., 2009b). This study illustrates the important role of money not simply as a means to financial sufficiency, but also as a symbolic representation of social value and self-worth. In this dissertation research it will be interesting to explore the extent to which outcomes of entrepreneurial “success” are measured in money or profit versus indicators of productivity, satisfaction, and purposefulness, and subsequently the extent to which they overlap.
Meaning is a very personal and subjective quality and is partially the reason why issues left open to interpretation frequently prove problematic. For example, Clegg et al. (2008) found a tension between how young adults with severe ID and their parents talked about work. Parents were more concerned with social inclusion and belonging than individualism. While people with ID valued work experiences, few parents thought it was a realistic goal. For many parents, employment was seen as an ideal world option and, when interviewed, the majority expressed little hope in this regard. There were some, however, who hoped their child would go to college and develop the necessary skills to pursue employment. While the severity of the respondents’ intellectual disability level could serve as a potential limitation of Clegg and colleagues’ study, it bears mentioning that self-employment has been suggested as a way to productively engage people with more severe disabilities who might otherwise be unable to work (Rizzo, 2002). The contribution this study makes to the current research is in illustrating the importance of recognizing the distinction between the perspectives of social entrepreneurs with ID themselves and those of individuals supporting their entrepreneurship. Both are important and offer valuable information in understanding how people with ID participate in social entrepreneurship, but it is critical that this distinction be properly contextualized. This will be accomplished by conducting in-depth interviews with individuals with ID.

F. **Employment Opportunities and Barriers**

Social entrepreneurs with disabilities represent a source of innovation and productivity and, if offered the appropriate resources, social entrepreneurship is an employment strategy that can lead to economic self-sufficiency and empowerment (Bichard, 2008; Lind, 2004; Office of Disability Employment Policy, 2007). However people with disabilities experience attitudinal and systemic barriers to business development, such as low readiness level (i.e., inexperience
with business start-up, management, and technical assistance). Similarly, training and ongoing support have been shown to facilitate entrepreneurial success with people with disabilities (Blanck et al., 2000; Lind, 2004; McNeill, 2009; Walls, Dowler, Cordingly, Orslene, & Greer, 2001), but disadvantaged people do not always have equal access to information about how to receive support or where to participate in training programs (De Clercq & Honig, 2009).

1. **Opportunities and incentives to employment**

   Beyond monetary personal gain, employment holds the potential to further social participation and community integration. Even unpaid, part-time, or voluntary forms of work can help people with disabilities develop skills to better compete in the job market. Work affords one the opportunity to feel like a meaningful and productive member of society.

   *Incentives* refer to policy strategies intended to indirectly improve employment outcomes for people with disabilities and come in two varieties: business incentives and individual incentives. Incentives for businesses are directed towards small businesses and include tax deductions and credits which encourage employers to hire people with disabilities and provide accommodations to customers and workers, as well as make facilities and transportation accessible. These incentives include the Work Opportunity Tax Credit, the Disabled Access Credit, and the Barrier Removal Deduction Program (Ozawa & Yeo, 2006). Nevertheless, most policies and programs focus more on the individual rather than on employers (Livermore & Goodman, 2009). Individual work incentives for people with disabilities include asset development, the Ticket to Work program and Work Incentives Improvement Act, planning and assistance programs, SSI/SSDI, and certain tax credits (Disability.gov, 2010).

   Social security is the most common form of income for non-working people with disabilities (47%) (National Organization on Disability, 2010). Work incentive programs that
fall under this umbrella of SSI/SSDI includes Plan for Achieving Self Support program (PASS), which allows individuals to exclude money, resources, and expenses from calculations of earned income; the Impairment-Related Work Expense program (IRWE), which allows one to exclude the costs of impairment-related services or items needed to earn income; Section 1619(a), which allows people to continue receiving supplemental income even if their earned income is at SGA; and Section 1619(b), which allows people to continue receiving Medicaid even if they no longer qualify for supplemental income (Livermore & Goodman, 2009; National Council on Disability, 2005).

The Ticket to Work program and Work Incentives Improvement Act demonstrate a shift in U.S. policy away from dependence on government entitlement programs such as SSI/SSDI, towards increasing workforce participation (Blanck, Clay, Schmeling, Morris, & Ritchie, 2002). Under the Ticket to Work program, people receiving disability insurance receive a voucher that can be used to purchase services from providers in an Employment Network (EN) without fearing they may lose their benefits for eligibility. This ticket can be used directly towards VR services (Butterworth, Smith, Cohen Hall, & Winsor, 2009) and can also act as an employment incentive by allowing clients to purchase Medicaid health insurance. Despite the potential benefits, the Ticket to Work program remains overwhelmingly underused because most ticket recipients are either unaware it exists or do not know how to use their tickets (Blanck et al., 2002).

The benefit of these policy programs is that they could be used to help mitigate the costs and risks associated with starting up a business. The Ticket to Work program in particular could be a useful tool for people with disabilities interested in pursuing self-employment and entrepreneurship, especially during the development and start-up phase of their organization. It
could be used with VR agencies to gain skills, assistance, or support that can not only benefit them personally as well as their business (Dyda, 2008). However, many people with disabilities, particularly those with cognitive impairments, have difficulty understanding and navigating this veritable alphabet soup of support (ARC, 2010) and it is unclear what efforts have been made to make this information available and accessible.

Self-employment and entrepreneurship hold many benefits for people with disabilities that conventional employment does not. Such benefits include greater independence and the opportunity to make one’s own business decisions, the ability to set one’s own pace and schedule, a reduction of transportation problems when a business is home based, and continued support from SSI/SSDI (Office of Disability Employment Policy, 2001).

2. **Barriers and disincentives to employment**

   The barriers to employment for individuals with disabilities often seem to outweigh the benefits; contributing significantly to the rate of unemployment and the social issues attendant. Barriers to employment do not just effect being able to find or maintain employment, they also effect job choice. Issues regarding transportation, health concerns, and financial disincentives limit one’s options for productive engagement and may also limit the number of hours spent participating (Lysaght et al., 2009b). In evaluating federal employment promotion programs and policies, Livermore and Goodman (2009) compiled a list of significant potential barriers and disincentives:
While this list is not exhaustive, it provides some indication of the range of barriers people with disabilities encounter in the pursuit of employment. The National Council on Disability (2007) highlighted several key barriers and challenges that range from the extra costs of work, which have been shown to be higher for people with disabilities, to the need for increased flexibility, the need for accommodations, the lack of information coupled with lower levels of education and training as well as concerns regarding disability income and healthcare, employer discrimination and reluctance to hire people with disabilities.

People who rely upon the use of assistive technology (AT) experience an additional cost to self-employment. A study comparing AT use in employment between veterans and civilians with spinal cord injury and found that the average cost of AT for people who were self-employed
was 68% to 124% greater than for any other type of employment. Such a large additional cost could very well act as a disincentive or barrier to people with disabilities seeking self-employment (Hedrick, Pape, Heinemann, Ruddell, & Reis, 2006).

Perceived barriers also play a significant role in determining employment outcomes. In a study of objective versus perceived career barriers among VR closures, Fabian and colleagues (Fabian, Ethridge, & Beveridge, 2009) made a distinction between external barriers such as environmental and workplace supports that include transportation, accommodations, job opportunities, and internal barriers that encompass self-perceptions of work experience, work skills, and vocational beliefs. They found self-reported perceptions of career barriers, such as gender, prior work history, and educational background, to be mitigated by social support factors. Regarding gender, female gender was associated with higher levels of perceived barriers. It is interesting that race was not an independent factor; however, minority females were found to have the highest level of perceived career barriers and non-minority males were not statistically significant. In relation to prior work history, they found a positive correlation between perceived barriers and the length of time a consumer had been away from the job market. That is, unless they had been away for longer than twelve years and had unrealistic expectations about returning to employment. However, research also suggests that work experience may actually act as a suppressor variable during quantitative analysis, mitigating the predictive validity of other variables (Martz, 2003). The exploratory nature of qualitative analysis will benefit this dissertation research in understanding the perceived barriers experienced by social entrepreneurs with ID in a way that allows for flexibility to accommodate for mitigating factors that invariably exist in such an under-researched topic. Accordingly, understanding the effect of such factors should strengthen rather than undermine the validity of
the study. Further, interpreting studies, such as those presented, using the entrepreneurial framework of motivation, management, and outcomes allows one to question whether barriers have a temporal nuance or whether they extend across these three foci.

G. **Opportunities and Barriers to Self-Employment and Entrepreneurship**

Entrepreneurship can be fostered as a vehicle for innovation and attitudinal change. People with disabilities who are unable to find meaningful work often become frustrated; wanting to work, to participate, and to have the opportunity to contribute to the economy as taxpayers and employers. The limited opportunities in traditional employment for people with disabilities and the promise of increased flexibility that self-employment offers are themselves powerful incentives and disincentives to entrepreneurship (Blanck et al., 2000). Griffin and Hammis, two disability-specific employment consultants who specialize in self-employment and authored the book *Making Self-Employment Work for People with Disabilities* (2003), note along with Wehman that,

> Self employment holds the promise of financial equity, contains unique opportunities under the Social Security Act, and presents options for personalized accommodations not easily found in wage employment. These factors, coupled with the desire to expand the possible range of employment choices allowed self employment to grow. (Wehman, Griffin et al., 2003, p. 143)

It is clear that entrepreneurship holds many potential benefits for people with disabilities that conventional employment does not, such as greater independence and the opportunity to make one’s own business decisions, the ability to set one’s own pace and schedule, a reduction of transportation problems when the business is home based, and continued support from SSI/SSDI (Office of Disability Employment Policy, 2001). It allows people with disabilities to “self-accommodate” by utilizing creative work arrangements (Blanck et al., 2000).

Barriers effecting entrepreneurship for people with disabilities include the possible loss of cash benefits from SSI/SSDI programs; possible loss of health care benefits; possible loss of
housing and other subsidies; and inability to access start-up capital due to poor credit ratings, lack of collateral, cash benefit programs that do not provide sufficient funds, and income support programs limiting the amount of assets a person can accumulate. Obstacles also include the unavailability of bonding; inability to obtain insurance; restricted access to support networks; lack of knowledge about bidding opportunities; and discrimination (Office of Disability Employment Policy, 2001).

It is not uncommon to encounter employment programs that do not support or encourage entrepreneurship. Further, those programs that do promote self-employment and small business development historically have not been receptive to business-owners with disabilities (Office of Disability Employment Policy, 2001). For many individuals with disabilities, one of the largest barriers to entrepreneurship is the lack of information or informational resources necessary to start a business or to develop their business plan (Doyel, 2002; Office of Disability Employment Policy, 2001; Walls et al., 2001). Without this they cannot take the first step towards social entrepreneurship; belying the systemic nature of these specific barriers.

A handful of studies have identified opportunities and barriers specific to self-employment and entrepreneurship, which complement the compilation presented previously (for a full comparison please see Parker Harris et al., in press). The scope of this research ranges from the experiential knowledge of a business-owner with disabilities (Doyel, 2002) to a policy analysis of self-employment as a VR closure option (Arnold & Seekins, 1994) and includes interviews with individuals who have acquired work disabilities (Blanck et al., 2000), interviews with individuals who have cognitive disabilities (Hagner & Davies, 2002), and online focus groups with individuals who use augmentative and alternative communication (AAC) (McNaughton, Light, & Arnold, 2002). This dissertation research will add to and further
develop those opportunities and barriers identified in the existing literature. It will also extend the research currently being generated by the larger project to fill the gap in our knowledge regarding the opportunities and barriers encountered by social entrepreneurs with disabilities to include individuals with ID in a meaningful capacity.

H. Contemporary Policy: The Potential of Entrepreneurship

The 1980’s saw a growth in entrepreneurial activity worldwide. While the exact cause is unclear, this phenomenon may have been the result of an ideological shift from Keynesianism to neoliberalism, the revival of small business, an increased emphasis on change and innovation to compete in the marketplace, or the encouragement of business and job creation in an effort to neutralize concerns over unemployment given a declining industrial labor force (Swedberg, 2000). In this difficult economy, both the government and private sector are reducing their workforce and utilizing contingent employment arrangements such as temporary, part-time, and contract employees (Office of Disability Employment Policy, 2001). Overall changes in employment in the general population are reflected in the growing trend towards self-employment and entrepreneurship for people with disabilities as well. An essential component of a healthy economy, as a source of business and job creation, entrepreneurship has often been encouraged as a strategy to reduce unemployment (Swedberg, 2000). Yet, in the past, self-employment and entrepreneurship have often been overlooked by government programs and underutilized as a VR strategy for people with disabilities (Doyel, 2002; Kendall, Buys, Charker, & MacMillan, 2006; Office of Disability Employment Policy, 2001; Parker Harris et al., in press; Walls et al., 2001). Governments are now looking for more innovative policy solutions to ameliorate pressing social and economic issues, and attention is being increasingly directed towards the potential of social entrepreneurship.
In 1999, the Department of Labor found that people with disabilities were almost twice as likely to be self-employed than those who were not disabled (Blanck et al., 2000). This may be due in part to the implementation of enterprise development programs recommended to the Small Business Administration and U.S. Department of Education by the Department of Labor’s Glass Ceiling Report in the early nineties. These programs were proposed as a method for increasing leadership and employment opportunities for people with disabilities and their success was stated to require four components: 1) the sources of capital to finance business operations, 2) the ability to obtain the necessary technical assistance, 3) the use of small business incubators to organize technical assistance and to provide a supportive environment for business startups, and 4) the organization of these components within a Community Development Corporation (Braddock & Bachelder, 1994).

Entrepreneurship has become part of the nationwide strategy to address the disparities in employment for people with disabilities (for a thorough review please see Parker Harris et al., in press). Particularly, to help transition from unemployment and underemployment, thereby reliant on entitlement-based programs, towards programs that foster self-sufficiency and offer the opportunity to achieve gainful employment (Blanck et al., 2002; Blanck et al., 2000). The national commitment to social entrepreneurship is reflected in the recent opening of the Office of Social Innovation and Civic Participation by the Obama Administration. In Illinois, a new “L3C” law took effect at the start of 2010 and aims at improving social entrepreneurs’ prospects for raising funding by creating a new category of a nonprofit and business hybrid: for-profit ventures with a social mission (Lane, 2008; Limited Liability Company Act, 2009).

State policies supporting self-employment and entrepreneurship for people with disabilities play a role in preparing service providers to support such initiatives; partially
accounting for the distinct variation in successful ventures between states (Revell, Smith, & Inge, 2009). A study conducted by the Vermont Department of Vocational Rehabilitation found that, during the first three years of the Vermont Choice Project, 75% of business start-ups developed out of the two regions where counselors benefitted from self-employment-specific experience and training (Collins in Blanck et al., 2000). Some researchers have focused on providing VR counselors with the experience, training, and expertise to support self-employment as an option for their clients. Watson and Herkimer found that successful counselors at a center for independent living (CIL) in Berkeley, California were those with an understanding of business planning, knowledge of community resources, the ability to coordinate financial and community resources, and the knowledge to coordinate SSI, SSDI, Medicare, Medicaid, and other assistance programs within these business plans (Watson & Herkimer in Blanck et al., 2000).

It is imperative that we understand how disability policy impacts people with ID, particularly those policies that were not written or amended to address the issues or needs specific to that group. If entrepreneurship is beneficial for people with disabilities in general then logically it follows that it should be similarly beneficial for people with ID as well. However, people with ID have a different history of employment and encounter different systemic social and environmental barriers that people with disabilities in general may not experience. For example, there is no mention of guardianship in the literature or policy regarding self-employment or entrepreneurship for people with disabilities or how that might affect ownership decisions. Discourse on employment and disability requires contextualization within theoretical literature and applied research on ID, else it contributes to the further marginalization of this already disenfranchised and neglected social group.
I. Contextualizing Employment and Intellectual Disability

The history of people with ID in the U.S. is invariably one of employment, or rather of their exclusion from employment and other areas of social participation. Although today we are familiar with the concepts of community-integrated living in deinstitutionalization, many institutions actually began as a way of providing people with ID skills so that they could be fully integrated into the community. However, over time these training schools became synonymous with unethical behavior and inhumane conditions (Braddock & Parish, 2001; Carey, 2009; Trent, 1994). Further, deinstitutionalization posed a unique problem to the question of employment in the face of increasing necessity and demand for opportunity and support (Braddock & Parish, 2001; Carey, 2009; Mansell, 2006; Trent, 1994). Now that more people with ID were living in the community, many wanted and needed to work; to participate gainfully and meaningfully (Butterworth & Boeltzig, 2008; Clegg et al., 2008; Jahoda et al., 2009; Lysaght, Ouellette-Kuntz, & Morrison, 2009a; Migliore, Mank, Grossi, & Rogan, 2007; Murphy, Rogan, Handley, Kincaid, & Royce-Davis, 2002) – as full citizens.

While self-employment and entrepreneurship continue to be a growing trend, they are being offered, provided, and supported inconsistently (Arnold & Ipsen, 2005). More recently, in the disability sector there has been an emphasis on social entrepreneurship; a business intended to not just generate monetary profit, but to do so with a primarily social mission. Social entrepreneurship has become a phrase gaining momentum in the ID community (Bichard, 2008; DisabilityWorks, 2008; Easter Seals Metropolitan Chicago, 2011; IFF, 2000; Pavey, 2006; Ray Graham Association, 2009; Reid, 2004; Seguin Services, 2011); one that carries with it a very distinct history.
While living in institutions, people with ID did work; however, it was not necessarily paid or compensated. In many ways, people with ID have always “worked” even if not employed. Often their work was considered compensation to the institution for services provided. Such practices were touted as facilitating the development of work skills and enabling individuals with ID to be productive, active, and contributing members of society (within the institution) by landscaping, farming, and growing their own food or products that could be sold to the surrounding community (Trent, 1994). Also, it was not uncommon for part of the daily activity in institutions to involve individuals with ID creating goods that the institution would then sell to supplement their income and offset their expenses (Friedman, 1943; Grimes, 1922; Reaume, 2004; Tyor & Bell, 1984). Such practices took place under the auspices of philanthropy and contributed to the development of sheltered workshops as we know them today. This approach to employment for people with ID merits further attention in order to better understand how the tenets of social entrepreneurship have been misused and applied paternalistically to suppress the social participation of people with ID.

Whereas for people with disabilities in general the primary benefit of self-employment and entrepreneurship is that it offers opportunities that may not be found in traditional, competitive employment (Blanck et al., 2000; Doyel, 2002; Ipsen, Arnold, & Colling, 2005; Office of Disability Employment Policy, 2005), the overarching concern for the ID community is twofold. First, that policy is being created for people with disabilities in general that is directing funding and affecting the ID community and employment service providers without necessarily recognizing their distinct needs. Second, that social entrepreneurship is being used as a way to repackage employment strategies that have historically segregated and oppressed this population. The key to this distinction lay in recognizing the difference between social enterprises that are
created for versus those created by people with disabilities. Social entrepreneurship for people with disabilities is a customized employment strategy that should be both self-directed and person-centered. It bears consideration that, in many ways, people with ID have always worked; even if that work was not deemed valuable, productive, or considered employment/employable in the mainstream labor market. People with ID and their families may have long been entrepreneurial because they have had to be innovative to work within a society that systematically disadvantages and undervalues them. Subsequently, social entrepreneurship has both the potential to be empowering as well as potential to be oppressive.

While this research cannot definitively answer these larger epistemic questions, it offers a place to begin addressing current gaps in our knowledge and from which to identify avenues for future inquiry. Moreover, citizenship theory contributes to the development of under-theorized areas of disability policy by superseding ostensible policy silos in the interest of actualizing theories of democratic membership in society and participatory parity (Berube, 2003; Fraser & Honneth, 2003; Lovell, 2007; Parker Harris, Owen, & Gould, 2012). It is crucial that, in moving forward towards the goals of community integration and social participation, policymakers and service providers take care not to inadvertently perpetuate existing models of oppression, particularly as regards the social and economic participation of people with ID in employment.

1. **Integrated versus segregated employment debate**

   Employment for people with ID can be generally separated into three categories: segregated work environments, integrated work environments, and nonwork environments such as day training programs or volunteer work (Metzel et al., 2007). Segregated environments are facility-based and often referred to as sheltered workshops or congregate settings wherein people
with ID work and socialize with others with ID. Because nonwork often occurs in facility-based, congregate settings as well it is sometimes included in descriptions of segregated environments.

*Integrated employment* includes both individual employment and group-supported employment (Sulewski, Butterworth, Gilmore, & Taylor, 2008; Winsor & Butterworth, 2008). “Integrated employment services are provided in a community setting and involve paid employment of the participant. Specifically, integrated employment includes competitive employment, individual supported employment, group supported employment, and self-employment supports” (Butterworth et al., 2009, p. 15). *Community-based, nonwork* is defined as services that are located in the community, not a facility, that do not involve paid employment but includes general community activities, volunteering, or recreation and leisure participation (Sulewski et al., 2008; Winsor & Butterworth, 2008). “Community-based nonwork includes all services that are focused on supporting people with disabilities to access community activities in settings where most people do not have disabilities” (Butterworth et al., 2009, p. 15). *Facility-based work* includes employment services that take place within segregated settings where the majority of employees have a disability and where continuous job-related supports and supervision are provided to all workers with disabilities. Typically this service category is referred to as a Sheltered Workshop, Work Activity Center, or Extended Employment program (Butterworth et al., 2009; Sulewski et al., 2008; Winsor & Butterworth, 2008). *Facility-based nonwork* “includes all services that are located in [segregated settings] where the majority of participants have a disability and does not involve paid employment of the participant” (Butterworth et al., 2009, p. 15). For example, day habilitation or day activity programs (Butterworth et al., 2009; Sulewski et al., 2008; Winsor & Butterworth, 2008).
The establishment of sheltered workshops pre-dates the deinstitutionalization movement. In the late 1950’s, the Office of Vocational Rehabilitation expanded services to include individuals with ID. The increased federal funding provided through this initiative went towards the creation of an employment model that would meet the need to provide post-school work-related services to people with ID – sheltered workshops. Originally, sheltered workshops were intended to provide people with ID a space to learn and work at their own pace (Carey, 2009). Indeed, workshops habitually experience significant periods of time where there is no work to be done. Some families find it reassuring that workshops provide “structure” during periods of downtime (Migliore, Grossi, Mank, & Rogan, 2008). While sheltered workshops became and remained the dominant employment model for people with ID, their purpose was re-envisioned in the Rehabilitation Act, as deinstitutionalization and community integration gained momentum, to provide an alternative for those individuals who could not participate in integrated employment:

The passage of Section 504 promised to open employment opportunities to people with disabilities, yet it had a limited impact on the employment of people with mental retardation, as they were rarely seen as “otherwise qualified” for employment. Ironically, the same act channeled money into sheltered workshops, maintaining them as the dominant model of employment for this population. Ideally, sheltered workshops provided appropriate work training and employment opportunities for those who were unable… to work in the competitive labor market. However, they also isolated people with disabilities, paid little, and maintained for them a separate system of employment with few opportunities to learn the skills needed for competitive work placements. (Carey, 2009, pp. 168-169)

From a systems change perspective, this policy shift to integrated employment was supposed to succeed segregated arrangements and, with the exception of the “neediest” cases, gradually phase out sheltered workshops (Carey, 2009; Migliore et al., 2007). However, workshops continued to receive funding resulting in a dual system presenting both as viable options (Migliore et al., 2007).
There continues to be disagreement over whether people with ID benefit most from an integrated versus segregated work environment; most notably in an exchange of journal articles between Butterworth et al. and Weikle (Butterworth & Boeltzig, 2008; Weikle, 2008). Results of the instigatory study (Metzel et al., 2007) reported that, of a national sample of Community Rehabilitation Providers (CRP), there has been little change in the rate of participation in integrated employment for people with ID (26%). When taken in context with the rate for facility-based work (41%) and non-work (33%), the authors argue that funding should be reallocated towards programs and services supporting integrated employment and away from facility-based day programs. Notably, for every one person with ID working in competitive employment, there are three in segregated work settings (Migliore et al., 2007). Butterworth and colleagues argue that this change in funding is a necessary step towards achieving community inclusion and membership.

To this Weikle challenges the researchers’ underlying assumption that congregate work settings were inherently “bad” or less valuable than integrated environments (Weikle, 2008). After all, segregated work provides a service for families and consumers as well as the opportunity to socialize with others with ID and create peer friendships. Redirecting funding away from facility-based programs would undoubtedly limit self-directed consumer choice. However, Butterworth effectively argues that a truly informed choice is already limited by the lack of resources for alternatives to facility-based segregated work and nonwork options (Butterworth & Boeltzig, 2008).

Offering a divergent perspective on the issue, Cummins and Lau (2003) approach the integrated versus segregated work debate by questioning whether participating in community living activities constitutes “integration,” or whether it is merely community exposure. By
community exposure the authors refer to instances where people are exposed to the general community without actually being socially integrated; thus making a distinction between physical community integration and a sense of community connectedness, personal interdependency, and belonging. The authors argue that physical community integration may not be optimal for people with ID. In general “communities” are self-chosen, based more on similarities than differences, whereas the process of deinstitutionalization constructed communities based on difference. Successful integration necessitates a “sense of community.” Their concluding remark is a bold statement that this sense of community is more likely to be found amid groups of people who have ID or their families. While this is quite an overstatement, it does force us to critically revisit preconceived notions and question whether the shift towards community integration may contain a paternalistic element previously not considered. Further, it can ignite a dialogue over the meaning of community membership and the value of both group differentiated and universal citizenship (Kymlicka & Norman, 1994).

Community continues to be defined for people with ID by service providers and policy makers (Cummins & Lau, 2003; Todd, 2000), which speaks to the phenomenon of people with disabilities having to live “in but not of” their communities (Milner & Kelly, 2009). An example may be found in Milner and Kelly’s study (2009) using a participatory action research (PAR) approach to explore how adults with disabilities define their place in the community in light of contemporary social policy. The researchers assert that the boundaries of community were defined by professional social practices rather than individuals with disabilities themselves, most of whom perceived community participation as another element of service delivery. This speaks to the assimilative nature of participation (Milner & Kelly, 2009; Todd, 2000). Participation is also, however, a political act (Beart et al., 2004; Milner & Kelly, 2009). While participation
occurs in this public “community,” a sense of belongingness and support were found in private or safe spaces – often among others with ID (Beart et al., 2004; Cummins & Lau, 2003; E. Hall, 2004; Milner & Kelly, 2009; Todd, 2000). While some scholars, such as Cummins and Lau, question whether integration is a forced choice rather than the realization of autonomous choice, it is has been suggested that it is not where, but rather how people participate that really matters (Milner & Kelly, 2009).

2. **Current employment landscape**

The Institute for Community Inclusion’s I/DD Agency National Survey of Day and Employment Programs for People with Developmental Disabilities identified several national trends in employment (Butterworth et al., 2009). According to the Survey, in 2008 the percentage of individuals receiving integrated employment services actually declined to 21.9% despite a modest growth in the number of people reported using integrated employment services. Facility-based work and non-work services have gradually declined, yet despite this decline there has been a growth in the use of community-based non-work (CBNW) services (Butterworth et al., 2009). These trends raise concerns because while CBNW can be a useful way to supplement employment supports for people who work part time, enable transition-aged youth to gain valuable work skills, or provide meaningful activity for people who are between jobs or unemployed; state agencies have been implementing it as an alternative rather than as a supplement to employment (Sulewski et al., 2008).

The model of employment people choose has been found to relate significantly to their reported levels physical and social integration. The most successful outcomes were reported for those using individual supported employment placements over any form of group support (Jahoda et al., 2008). **Supported employment** was one of the first integrated employment
strategies and provided entry for many into competitive employment and community integration (Wehman, Revell et al., 2003). This model aims to limit the impact of one’s disability on their productivity in the workplace by providing ongoing support to promote independence and employment stability. This involves conducting a detailed job analysis, the identification and use of community and workplace supports, systematic instruction, compensatory strategies, orientation training, and the provision of workplace accommodations (Wehman, Revell et al., 2003). The values of supported employment include presumption of employment; competitive employment; self-determination and control; commensurate wages and benefits; focus on capacity and capabilities; importance of relationships; power of supports; systems change; and the importance of community (Wehman, Revell et al., 2003). One strategy used in supported employment is the use of “natural supports” – people in one’s employment social network who can provide mentoring, friendships, and opportunities to socialize (Office of Disability Employment Policy, 2001). Job coaching has become an essential support mechanism in providing on-the-job training. A job coach helps employees with work-related tasks, helps provide transportation to and from the job-site, and may also help individuals learn and develop personal skills and other skills that will help maintain employment (O’Day, 2009).

Customized employment has gained considerable attention in recent years and involves individualizing the employment relationship. The principle behind this approach is that rather than expecting people with disabilities, or any employee for that matter, to fit a static job description, an employer can choose to take advantage of that employee’s strengths as well as meet their needs (Office of Disability Employment Policy, 2010). Job carving is a component of customized employment that is similar to job matching, wherein duties from existing jobs are combined into a new position that best fits the abilities of the individual with disabilities (O’Day,
2009; Wells, 2008). For example, Walgreens has developed an approach based on universal design principles and has begun redesigning the work stations at their distribution centers so as to remove as many barriers as possible and allow employees with and without disabilities to work alongside each other as peers. Walgreens’ goals are to integrate people with disabilities to fill one-third of their workforce and expand this practice to other branches of the organization (Leotta, 2007; Wells, 2008). Walgreens’ efforts demonstrate the benefits of customizing the workplace to meet the needs of employees much like job matching or carving customizes the job description to individual employees. Self-employment is similar to these employment options in that it involves accommodating for impairment through occupational customization; however, the scope is divergent. Social entrepreneurship refers not just to the individual or the environment within which they operate, but to the organization as well; complexifying the traditional employer-employee relationship. Understanding how people with ID are involved in the management process of social entrepreneurship, as possibly both employers and employees, will contribute to a more robust conceptualization of customized employment.

J. Conflation of Self-Employment and Social Entrepreneurship

Recently, a review of empirical self-employment research literature was conducted by Yamamoto, Unruh, and Bullis (2011), who found throughout the literature that self-employment, microenterprise, and entrepreneurship are used interchangeably. However, a reductionist approach conflates key distinctions between self-employment and entrepreneurship. Self-employment is defined as performing work for personal profit rather than for wages paid by others (Le, 1999). It is, first and foremost, an alternative strategy to salaried employment. Self-employment has been measured, for example, by the number of average weekly hours spent working for one’s own business (Kolvereid & Isaksen, 2006). The focus is on work – no matter
how productive or unproductive. However, entrepreneurship refers to bringing something new and innovative to the market, providing a clear differentiation from the concept of self-employment (Schumpeter, 2000; Shane & Venkataraman, 2000). Self-employment has limitations as an anti-poverty strategy given it is intended to employ one individual. The scope is not large enough to make an impact on unemployment, whereas due to the potential for both business and job creation, entrepreneurship can be an effective strategy in that regard. This indicates a discontinuity in policy and practice pertaining to the stated benefits that entrepreneurship hopes to achieve (Parker Harris et al., in press).

Self-employment and social entrepreneurship can both be used as customized employment options; tailoring not just a job to an individual’s interest or talent, but an entire business. However, it is important not to conflate the two or to assume that one necessarily follows the other. Despite the theoretical potential, self-employment and social entrepreneurship are not necessarily customized nor are they necessarily supported, competitive, gainful, or meaningful. Given the focus of VR providers on the intellectual capacity of the business-owner, self-employment and social entrepreneurship are often not offered for people with ID as an employment option (Wehman, Griffin et al., 2003). This is apparent in the number of VR self-employment closures for people with ID, 0.3%, the lowest across all disability categories (Revell et al., 2009). Regardless, social entrepreneurship has become an increasing trend among agencies providing services to people with ID in Illinois (DisabilityWorks, 2008; Easter Seals Metropolitan Chicago, 2011; Frechette, 2011; ICDD, 2008; IFF, 2000; Ray Graham Association, 2009; Seguin Services, 2011; The ARC of Illinois, 2010).

Given the current state of the economy, many service providers and community organizations struggle in the face of impending cuts to human services and are exploring social
entrepreneurship as a model that would allow them to continue operating to meet the needs of the communities they serve; offsetting costs and supplementing their bottom line by integrating a profit stream. As such, agencies providing employment services may be creating social enterprise programs that employ people with disabilities, but not necessarily as social entrepreneurs. This can lead to confusion regarding funding if money is going to support an organization itself rather than programs within organizations that promote social enterprise development among individuals with ID themselves. There is a need for clarification in policies that direct funding so that both service providers and individuals with ID can be adequately supported in pursuing social entrepreneurship.

The way that social entrepreneurship for people with ID is currently used in practice often includes scenarios that would be considered self-employment, job training, or skill development. This begs the question whether the social value component of these ventures is considered not to be generated by the person with a disability, but rather for them. Whereas critical theoretical distinctions should normally be made between self-employment, entrepreneurship, and social entrepreneurship; these become compounded in ID applications wherein the self-sustainability aspect of self-employment, the innovative aspect of entrepreneurship, and the social value generating aspect of social entrepreneurship need not necessarily be met in order to use this term – treated as if conditionally exempt. This raises concerns with regards to independence and self-determination, two elements that entrepreneurship promotes for people with disabilities in general. For this reason, we need to better understand how people with ID are participating and supported in social entrepreneurial ventures and how to engage with and incorporate entrepreneurship theory in Disability Studies research so as to make sense of this conflation rather than be mislead by it. For example, the
potential for job creation has been lauded as one of the benefits of entrepreneurship, not solely for people with disabilities (Blanck et al., 2000) but in relation to the general population as regards the health of the economy (Swedberg, 2000). While this potential for job creation is very likely a motivating factor in the promotion of social entrepreneurship for people with ID, it is unclear whether the justification is consistent with how such employment options are defined within entrepreneurship theory. Towards this end, citizenship theory can provide a constructive theoretical framework to explore complex issues, such as employment; structuring and focusing the discussion in a way that emphasizes rights and participatory principles.

K. **Integrating Entrepreneurship Theory**

As a discipline, entrepreneurship exists at the intersection of economic theory, the social sciences, managerial and organizational science (Swedberg, 2000); not only accounting for the rich and diverse nature of its theoretical development thus far, but also resulting in a fragmented research focus (Low & MacMillan, 2007; Schildt, Zahra, & Sillanpää, 2006; Shane & Venkataraman, 2000). Three major foci of entrepreneurship research comprise: 1) the causes of entrepreneurship, 2) entrepreneurial management, and 3) the results of entrepreneurship (Austin et al., 2006; Stevenson & Jarillo, 2007). Whereas the results of entrepreneurship are primarily concerned with impacts and outcomes of entrepreneurship, not necessarily the entrepreneur themselves, the causal element centers on the motivations of the entrepreneur from a more psychological and sociological perspective. Finally, the entrepreneurial management focus is process-based and concerned with how to foster innovation, organizational life cycles, and predictions of entrepreneurial success. These foci echo the disciplinary divisions mentioned previously and accordingly each offers a different standpoint from which to explore and define “success” in entrepreneurship. Incorporating elements of all three perspectives as motivation,
management, and outcomes, will allow this research to triangulate the issue at hand and gain a holistic perspective of what “success” means for people with ID participating in social entrepreneurial ventures.

1. **Entrepreneurship theory and participation in the political economy**

   Historically there has been a tendency to conflate entrepreneurship with the capitalistic impulse. This can be seen in how social theorist Max Weber defined entrepreneurship in the early twentieth-century as, “the taking over and organization of some part of an economy, in which people's needs are satisfied through exchange, for the sake of making a profit and at one's own economic risk” (Weber, 1990, p. 57). Such confusion is unsurprising given the role that entrepreneurship has played, and continues to play, in the development of capitalism. For Weber, the entrepreneur could only exist in an exchange economy wherein the role of entrepreneurship has less to do with any single individual than it does with the reactions of enterprises to market opportunities. The role of the entrepreneur within the economy is therefore to restore and maintain equilibrium (Swedberg, 2000) and thereby help to maintain the health of the economy. A contrasting and more individual approach, introduced by economic theorist Joseph Schumpeter, focuses on the entrepreneur as innovator. The role of the entrepreneur within the economy, in this view, is to disrupt the equilibrium through innovation and change (Schumpeter, 2000; Swedberg, 2000).

   This tension is particularly interesting to consider in the context of people with disabilities given the role ascribed to them in political-economic theory; maintaining the economy by remaining unemployed and acting in a Marxian capacity as a surplus population and reserve army of labor (Abberley, 1998; Charlton, 2006; Gleeson, 1997; Tremain, 2005). This acts to oppress people with disabilities as a class in capitalist societies wherein they remain poor
and unemployed, not necessarily recognizing the right of people with disabilities to work. Exacerbating this phenomenon is the stigma of welfare attendant to those “dependant” upon public services. Effectively, economic theory relies upon people with disabilities remaining unemployed and dependent upon services, thereby offering little opportunity to get out of poverty. It is then ironic that entrepreneurship has been encouraged as just such an opportunity. Entrepreneurs with disabilities therefore represent a theoretical anathema; raising the question of whether this shift in policy represents a shift in the position of people with disabilities in the political-economy, or whether it instead creates an untenable stalemate that prevents social mobility.

Weber positioned the entrepreneur oppositionally to the bureaucrat in an increasingly rationalized society. Whereas bureaucracy posed a threat to economic progress, the entrepreneur held the potential to counterbalance it (Brouwer, 2002; Swedberg, 2000). Thus, it is the responsibility of the entrepreneur to regulate the bureaucracy/state. However, according to Schumpeter, there is a “creative-destructive” process involved in modern capitalism (Dees, 2001; Radford, 1994), wherein an entrepreneur acts as the change-maker of the economy and is accordingly responsible for moving the economy forward through innovation by serving new markets by creating new ways of doing things. Schumpeter observed that prior economic theorists assumed the economy to be merely a static, reactionary system acted upon by external forces. Such a conceptualization cannot account for change (Brouwer, 2002; Schumpeter, 2000; Swedberg, 2000). Consequently, he developed an economic theory that recognizes internally generated change centered on the entrepreneur – entrepreneurship as innovation (Schumpeter, 2000; Swedberg, 2000).
Overall, Schumpeter’s interest focused on understanding the reaction or resistance of the social environment against an individual who wants to introduce something new, which is why he highlighted the motivations of the entrepreneur. The final element of his typology, the impact of the social environment, addresses the ways in which institutional factors affect entrepreneurship and the health of the economy. What Schumpeter overlooks, however, is the extent to which institutional social factors limit the ability of oppressed populations, such as people with disabilities, to participate in entrepreneurship. While in Weber’s estimation entrepreneurship provided a vehicle for religious minorities to participate in the economy when other avenues of social advancement were closed to them, Schumpeter’s entrepreneur has been depicted as a creative non-conformist, embraced by the financial community, rather than as a member of a group that has been marginalized and disenfranchised (Brouwer, 2002). It is important to consider the ways in which both entrepreneurship theory and disability theory refer to a necessary subversion of the status quo (Albrecht, Seelman, & Bury, 2001; Davis, 2006b; Goodley, 2010); particularly as it relates to participation in the workforce (Barnes & Mercer, 2005; Blanck, 2000; Charlton, 2006) and through entrepreneurship specifically (Blanck et al., 2000; De Clercq & Honig, 2009).

2. **Entrepreneurial motivation: “Why they act”**

There are many factors affecting people motivated to pursue entrepreneurship. It is unsurprising then that this focus has been referred to as causal, considering why entrepreneurs act (Stevenson & Jarillo, 2007). According to Schumpeter, entrepreneurs are driven by three motivations: 1) the desire for power and independence, 2) the will to succeed, and 3) the satisfaction of getting things done (Swedberg, 2000). Moreover, social entrepreneurs are motivated by lived experiences; their mission related and interwoven with social value (Austin et
al., 2006; Bornstein, 2007; Bornstein & Davis, 2010). It has been said that a “moment of obligation” causes one to change their life path and pursue work of deep personal significance (Bornstein & Davis, 2010; Dorsey, Galinsky, Cheadle, & Prendergast, 2006). For instance, blocked social and economic mobility has acted as a catalyst for business activity and the acquisition of business skills among ethnic minorities (T. Bates, 1997; Waldinger et al., 2000). Events such as traumatically acquired disability (Haynie & Shepherd, 2011) or perceived hiring discrimination on the basis of one’s disability (Blanck et al., 2000) may serve as the impetus driving an individual to pursue entrepreneurship.

One tool that has proven effective in focusing research on entrepreneurial motivation has been a *Push-Pull* conceptualization. In their research, Haynie and Shepherd (2011) examined the career transition period for veterans with acquired disabilities in response to traumatic life events and observed a strong link between career and identity during this transformational period. During the course of the study two types of motivations emerged: entrepreneurship as a career path based on perceived or real obstacles to other career paths (Push Motivation) and entrepreneurship as a career path based on satisfying some psychological need rooted in trauma and transition (Pull Motivation). Pull factors are typically considered to be positively motivated whereas push factors imply that self-employment is chosen under duress, despite one’s preference and due to a lack of other options (T. Bates, 1997). For people with ID, it is anticipated that the research will find motivation in pursuit of community integration and social participation.

Push-pull factors also benefit from an interpretation that utilizes social psychological literature on intrinsic and extrinsic motivation. For instance, pull factors are believed to be internally motivated whereas pull factors are believed to be due to situational or environmental
phenomena (Gilad & Levine, 1986), such as barriers to participation in employment. This conceptualization holds potential to raise some interesting questions during analysis regarding the application of a social model of disability in addressing this issue. Further, the integration of a Disability Studies approach to this thread in entrepreneurship research will contribute to its’ theoretical development.

3. **Entrepreneurial management: “How they act”**

Research on the process of entrepreneurship, considering how entrepreneurs act, is largely normative (Stevenson & Jarillo, 2007); concerned primarily with understanding what management factors contribute to entrepreneurial success. Subsequently, the goal of such research traditionally is to produce findings that are replicable and generalizable that other entrepreneurs might use to be successful in their ventures. However, when discussing entrepreneurship within the context of ID an additional element is imputed – that of support. The pivotal question then becomes how the process of entrepreneurship is being supported for people with ID.

Supported employment was one of the first integrated employment strategies for people with ID and provided entry for many into competitive employment (Wehman, Revell et al., 2003). Supported employment aims to limit the impact of one’s disability on their productivity in the workplace by providing ongoing support to promote independence and employment stability. Past research has shown that the model of employment people choose relates significantly to their reported levels of physical and social integration. The most successful outcomes were reported for those using individual supported employment placements over any form of group support (Jahoda et al., 2008). It is not yet understood how these findings translate to entrepreneurship.
Through conducting interviews with eight business owners with cognitive disabilities, Hagner and Davies (2002) sought to gain an understanding of participants’ perspectives in what has become a growing trend in VR service provision – supported self-employment. Questions focused around the meaning of self-employment for these business owners as well as the structure, function, and viability of their businesses. They found that in making business decisions precedence was not given to income generation. For example, one participant accepted “donations” as payment because his parents feared he would lose his benefits and also because the developmental service agency hosting the venture feared that sales would affect their non-profit status. This raises significant questions regarding the meaning of “success” not just from the perspective of the business owner themselves, but also from the perspectives of those supporting these ventures.

The researchers also focused on exploring what kinds of supports are provided and how they are being used. For instance, one strategy used in supported employment is that of “natural supports” – people in one’s employment social network who can provide mentoring, friendships, and opportunities to socialize (Office of Disability Employment Policy, 2001). In Hagner and Davies, while interviews centered on the individual business owners, they were also conducted with the individual identified as being the most closely associated with the provision of employment support. It was observed that VR professionals had difficulty appreciating the difference between traditional supported employment scenarios and self-employment. Further, because they did not have training specific to this area, they were operating outside their competencies, which limits professionals’ ability to support their clients effectively (Ipsen et al., 2005; Walls et al., 2001). In the past VR counselors have largely not been trained in small business development, specializing instead on expertise relevant to competitive employment.
(Ipsen et al., 2005). This illustrates how essential it is that we understand the ways in which the process and management of entrepreneurship is supported for people with ID.

4. **Entrepreneurial outcomes: “What happens when they act”**

Traditional outcome measures used in self-employment research for people with disabilities, as indicators of success, have included sustainability of the business, gross and earned income, provision of appropriate and affordable health benefits, integration and community activities, and reduction of governmental support (Arnold & Seekins, 1994; Blanck et al., 2000). However, many researchers who have tried to tackle the phenomenon of entrepreneurship among people with disabilities have found it difficult to develop meaningful outcome measures as stages of success used in traditional employment activities are limited in their application to self-employment. For instance, people with disabilities encounter a traditional-expectations barrier, which indicates a conflict with how they traditionally define success. Success for a new microenterprise may not mean growth so much as achieving self-sufficiency and being able to claim financial independence (Walls et al., 2001). Analyses must therefore extend beyond measures of economic growth to include measures of self-determination, quality of life, health, and other outcome factors (Blanck et al., 2000). This becomes further complicated when adding a social value component, which is itself difficult to measure (Austin et al., 2006). This leads us to question what “success” really means for people with ID involved in social entrepreneurship.

L. **Unpacking “Success”**

Traditionally, business approaches entrepreneurship through a linear process of causation, wherein a cause leads directly to an effect. However, Sarasvathy (2001) posits that rather than following an established linear trajectory wherein the effect is a given property and
the focus lies on what decisions are made towards achieving that effect (*causation*), an entrepreneur may choose to work with a given set of means and exploit contingencies towards the possibility of several possible effects (*effectuation*). Doing so would offer several advantages towards opportunity recognition and creation. By establishing a false dichotomy between causation and effectuation, Sarasvathy developed a theory of effectuation in the hopes of establishing a viable alternative to the traditional approach. The core theory of effectuation includes four principles: 1) affordable loss rather than expected returns; 2) strategic alliances rather than competitive analyses; 3) exploitation of contingencies rather than exploitation of preexisting knowledge; and 4) controlling an unpredictable future rather than predicting an uncertain one (Sarasvathy, 2001).

The theory of effectuation adds two insights to how we conceive of entrepreneurship. First, in a move away from viewing markets as homogenous collectivities, effectuation recognizes the diverse nature of firms, organizations, and human beings. Second, effectuation challenges conventional notions of entrepreneurial success. Often “success” is seen as the equivalent of “not failing.” However, because this theory appreciates the plurality of viable options given the set means and contingencies, an entrepreneur who employs effectuation will necessarily have a plurality of “failed” firms for every “successful” one. Not only are success and failure not dichotomous variables, but they are actually interdependent. Success of one option depends upon the failure of others.

Within the disability context, entrepreneurial success is dependent upon societal reciprocity – what is viewed as legitimacy or being legitimized by others. Entrepreneurs with a disability experience a tension between the ability to blend-in, or conform, and the desire to be perceived as innovators (De Clercq & Honig, 2009; De Clercq & Voronov, 2009). This
normative expression underlies a sense of entrepreneurial legitimacy that consists of two principal facets: both the need for entrepreneurs to fit in and stand out the same time.

Furthermore, by highlighting the importance of the entrepreneurs’ specific actions to comply with the demands for both stability (expectation to fit in – be good citizens) and change (expectation to stand out – innovate and challenge the status quo), while also noting the importance of factors outside their control (field maturity) and under his control (impression management), we suggest that the individual entrepreneurs are complicit in the dialectics of stability in change, inasmuch as they navigate institutional contradictions and conflicting demands. (De Clercq & Voronov, 2009, p. 411)

While this tension De Clercq and Voronov investigate between innovation and conformity is palpable for all social groups in a normative society, it is particularly salient for entrepreneurs with disabilities given the emphasis on normalcy and the stigma attached to disability as being somehow deviant or deficient (Davis, 1995, 2006a). The very premise of disability challenges the status quo and begs the question whether the propensity for innovation is higher among people with disabilities. However, there also exists a strong societal pressure to conform to normative, unrealistic ideals (Davis, 1995, 2006a). Subsequently, this phenomenon of “tension” extends our understanding of “success” beyond traditional outcomes of entrepreneurship to include the element of social reciprocity for people with disabilities as it relates to both social and economic participation.

Power is of critical importance in shaping entrepreneurs’ place in society. Due to differences in their position, relative to societal and normative structures of power, people with ID see the world from a different standpoint from those without. It is therefore essential to understand how people with ID view and construct their realities if they are to participate equally in society. In this particular context, how they construct outcomes indicative of “success” as it relates to their participation in society and the workforce as social entrepreneurs.

Achieving successful outcomes in employment is at the heart of disability employment research, policy, and practice. We want to know that the policies and programs that are being
developed and implemented are going to be effective at addressing the concerns around unemployment and underemployment for people with disabilities, and ID in particular. Yet, much of the research and development occurring in the area of self-employment, entrepreneurship, and social entrepreneurship is absent the voices and perspectives of people with ID. The purpose of this dissertation research is to understand what we mean when we talk about “successful” outcomes in social entrepreneurship, because there is been such a paucity of research in this area. This research will reify the concept by taking an abstract, theoretical potential employment strategy and exploring what people with intellectual disabilities are actually doing: how they are participating in social entrepreneurship and how they are supported in those efforts. The following chapter will detail how the research design draws upon Critical Disability Studies, informed by a conceptual framework, which centers ID within the context of Disability Studies and Entrepreneurship Studies, and a theoretical framework, which uses citizenship theory as a tool to challenge our understanding of social and economic participation as it relates to social entrepreneurship.
III. METHODS

This dissertation contributes to our understanding of social entrepreneurship and disability by introducing a component to the larger research project (PTI) that specifically focuses on understanding the experiences of social entrepreneurs with ID. This issue is particularly important given that policy and practices for people with disabilities and social entrepreneurs in general affect the way that people with ID are participating and supported in social entrepreneurship. However, to date the perspectives of people with ID have not been included in the development of policy and practice. This underscores the need for research that takes into consideration the voices of social entrepreneurs with ID regarding why they act (motivation), how they act (management), and what happens when they act (outcomes).

The experiences of seven people with ID participating in social entrepreneurship are explored using dyadic interviewing, a technique developed purposely for this research to address some of the difficulties that present when conducting interviews with individuals with ID. As will be explained in greater depth, dyadic interviewing is a qualitative methodology that recognizes there exists an interdependent relationship between individuals and embraces this phenomenon as a source of information rather than attempting to control for it. Accordingly, each set of interviews consists of a dyad that includes: 1) the individual with ID and 2) their key support person. A total of fourteen interviews were conducted with seven dyads. The process for recruitment and selection of participants is detailed later in this chapter. Qualitative methodology is most conducive to exploring the aims and objectives of this research given the under-researched nature of the topic and the heterogeneity of the unit of analysis.

2 This chapter includes information that has been published elsewhere: Caldwell, K. (2013). Dyadic Interviewing: A Technique Valuing Interdependence in Interviews with Individuals with Intellectual Disabilities. Qualitative Research, 1-20.
A. **Research Aims and Objectives**

The overall aim of this research is to explore the reification of “success” for people with ID participating in social entrepreneurial ventures; taking this abstract concept and situating it in the real world by addressing the following research questions:

1. How do people with ID experience social entrepreneurship, and are these experiences consistent with current understandings of social entrepreneurship?

2. What do social entrepreneurs with ID perceive “success” to be, and how does participation and support contribute to social entrepreneurs with ID’s perceptions of “success?”

3. What factors contribute to entrepreneurial motivation, and how do these factors affect “success” for people with ID?

4. What experiences of barriers and facilitators are raised in the process of entrepreneurial management, and how do these issues affect “success” for people with ID?

5. What do people with ID perceive the outcomes of social entrepreneurship to be, and to what extent do these perceptions of outcomes reflect “success” for people with ID?

In particular, this research seeks to understand how people with ID are participating and supported in social entrepreneurship, focusing on exploring the motivations, management, and outcomes and how they related to a broader understanding of “success” in disability employment and social entrepreneurship.

B. **Methodological Epistemology**

The methodology of this research is guided by an epistemology rooted in Critical Disability Studies, which functions to “connect the aspirations and ambitions of disabled people with transformative agendas of class, feminist, queer and postcolonial studies” (Goodley, 2010, p. 174). In this way, Disability Studies can draw upon the venerable foundation established by critical social theorists in other disciplines to advance the field; opening new modes of critical inquiry and reinforcing the interdisciplinarity of Disability Studies (Meekosha & Shuttleworth,
Its engagement with critical theory is what differentiates Critical Disability Studies from Disability Studies, looking at not only the individual or the structural environment, but at the individual within the structural environment. It is important to note that Critical Disability Studies is not separate from Disability Studies, but rather is a distinction among scholarship that recognizes the role of intersectionality and situated knowledge (Goodley, 2012).

People with disabilities have long been the subjects of research production, often not as voluntary and informed participants. The history of ethical violations in research involving people with ID in particular led to a critical period of change, between 1966 and 1976, catapulting the movement of biomedical research and ethics from the private to the public sphere and thereby leading to the development of research ethics as we know them today (Rothman, 2003). The Patients’ Rights Movement and the Disability Rights Movement both played a powerful role; acting as catalysts for change by drawing attention to the position of people with disabilities in research interactions and bringing visibility to the various ways in which people with disabilities were being exploited and disenfranchised (Carey, 2009; Longmore & Umansky, 2001; Nielsen, 2012; Noll & Trent, 2004).

Yet if people with ID are not involved in research then how are they to inform the production of knowledge that will affect them? Research plays a pivotal role in making the case for people with ID living and working in the community instead of being segregated and housed in large institutions. It is research that will determine policy that directs funding; that will provide for community-based resources, services, and support; that will determine best practices across the fields of healthcare, employment, and education among others. If people with ID are not involved, if they do not have a voice in the research driving policy and practice, then how can such research hope to achieve ecological validity and accurately reflect the lived experiences
of people with ID? How can research be evidence-based if it does not meaningfully include the
voices of people with ID, who have been so othered? Simply put, it cannot. Accordingly, it is
the responsibility of researchers working in the ID field to facilitate the involvement of people
with ID in their research in a way that this participation is not only done in accordance with
ethical practices, but that also is meaningful and representational.

Today it is the responsibility of an Institutional Review Board (IRB) to protect research
subjects, particularly those who are among populations that are vulnerable to exploitation
(Belmont Report, 1978). However, this continues to depict people with ID as passive
participants in research interactions. The field of Disability Studies was revolutionary in
embracing the emancipatory potential of research to include people with disabilities (Barnes &
Mercer, 1997). The emergence of an emancipatory paradigm in Disability Studies engaged
discussion among scholars about the role of power in the social relations of research production
(Oliver, 1997; Zarb, 1992).

Disability researchers walk a fine line between authentically capturing the actions of
participants and reinterpreting those actions in [ableist] terms that emphasize victim
images of disabled people. No researcher is infallible…. Disability research with
participants can fall into research on participants – when the only person benefiting is the
researcher and their career aspirations. However, critical reflections on subjectivity
permit us to at least start unpicking the aims, directions, and findings of research and the
researchers’ role in their creation. (Goodley, 1999, p. 43)

Disability studies scholars have asserted that it is not the role of the researcher to emancipate
people with disabilities. That presumption, in and of itself, is paternalistic. The researcher’s role
is not to empower people, but rather to facilitate this process for people who have already
decided to empower themselves (Oliver, 1992, 1997). For instance, social entrepreneurs who
have already taken a step towards economic and social emancipation.

One way in which research can contribute to combating the oppression of people with
disabilities is by “the development of a methodology and set of techniques commensurate with
the emancipatory research paradigm” (Oliver, 1997, p. 20). Dyadic interviewing, as detailed herein, challenges dominant research methodologies because it not only recognizes the inherent interconnectedness of people, but also because it does not impress upon people with ID the expectation that their “independent” participation must be done unsupported and thereby pressuring individuals with ID to conform to normative expectations regarding research participation. Accordingly, the role of the researcher is first and foremost to facilitate people with ID in sharing their experiences in social entrepreneurship and having their perspectives and voices heard.

However, as much as Critical Disability Studies embraces this emancipatory paradigm, it also challenges it by questioning its devaluing of the of the researcher’s conceptual contribution and critical-interpretive skills (Meekosha & Shuttleworth, 2009). This argument is particularly salient for work with individuals with ID wherein researchers are needed to interpret inaccessible academic information for use in unpacking and making sense of the experiences and perceptions of people with ID. Further, scholars are needed to reify that information, transcending the academe and making it accessible to service providers, family members, other support persons and professionals, and most importantly to the individual with ID themselves. Finally, it is also the researcher’s role and responsibility to publish that information and contribute the voices of individuals with ID to the production of knowledge. People with ID that want to participate in research do so largely because they want to improve their quality of life. They believe that this can be accomplished by helping researchers to understand their experiences and opinions (McDonald, Kidney, & Patka, 2012), so that their “situated knowledge” (e.g., Garland-Thomson, 2005) as a person with ID may be utilized to improve the lives of others with ID (McDonald, 2012; McDonald et al., 2012; E. L. White & Morgan, 2012).
Feminism has been instrumental to the development of critical theory and to Critical Disability Studies, particularly through the work of feminist Disability Studies scholars who challenge hegemonic normative notions of representation and difference; interrogate notions of care and dependence as well as power and privilege; and apply conceptual tools such as situated theory/standpoint theory (Garland-Thomson, 2005; Kittay, Schriempf, Silvers, & Wendell, 2001; Meekosha & Shuttleworth, 2009; Thomas, 1999; Wendell, 1996). Recently, an important theoretical connection has been made between standpoint theory and intellectual disability:

...the question of developing a standpoint epistemology for persons with intellectual disabilities presents even greater challenges. For one of the tacit assumptions in much standpoint epistemology is that the marginalized perspective and location of the individual is articulable by the individual herself. It is precisely because others have claimed to speak for and about certain groups that the space must be created for these voices to emerge. (Carlson, 2010a, pp. 127-128)

Similar to how standpoint theory has been used to give voice to other subjugated populations, so too can it be applied for people with ID. Discussion of voice is a fundamental methodological consideration for qualitative researchers working with individuals with ID given the extent to which historically their voices have been so pervasively silenced, segregated, and oppressed (Carey, 2009; Carlson, 2010b; Gibson, 2006; Malacrida, 2006).

The methodology of dyadic interviewing is informed by standpoint theory in that it recognizes the individual with ID’s agency in identifying the person they feel best supports them. Subsequently, doing so limits the potential for bias on the part of the researcher and support persons who may want to answer for the person with ID, in their “best interest” rather than respecting their choice of who they want representing and supporting their participation. The fundamental element of dyadic interviewing is that it’s very structure affords individuals with ID the opportunity to make that choice. This is not to say that the individual with ID cannot ask
their support persons for advice or for assistance in making the decision, but it ensures that
decision is the individual with ID’s first and foremost – it is self-determined.

Dyadic interviewing is also informed by disabled feminist scholars’ work on
interdependence. It is an interdependent methodology because instead of ignoring, attempting to
control for, or otherwise creating an illusory division between people, it recognizes the value of
interconnected relationships and contextualizes such in a way that retains focus on the person
with ID as the unit of analysis. Further, it does not hold people with ID to the unrealistic
expectation that they be “able” to participate in the interview while unsupported,
“independently.” For many, such expectations in and of themselves can be disabling in the
social model sense: creating a disabling environment wherein the researcher contributes to the
social construction of intellectual disability.

C. Use of Qualitative Methodology

The self-advocacy movement, in conjunction with the reception of participatory and
emancipatory paradigms in disability research, has led to the advancement of techniques to
meaningfully engage people with ID in research (Perry, 2008). Qualitative research is derived
from a phenomenological paradigm. Rather than the assumption that there exists an objective
reality consisting of social facts, as the positivist philosophy of quantitative research supposes,
qualitative methodology suggests that there are multiple realities that are socially constructed
(Firestone, 1987; Taylor & Bogdan, 1998). Both qualitative and quantitative methodologies
provide indelible and complementary information in their examination of an issue. While the
quantitative researcher uses objective empirical designs that focus on limiting bias to identify the
cause of social facts, the qualitative researcher allows themselves to become immersed in the
phenomenon they are studying in order to understand it from the perspective of those being
observed (Firestone, 1987; Taylor & Bogdan, 1998). Accordingly, qualitative research is not necessarily theory-driven, hypothesis testing, or generalization producing in the positivist sense (Denzin & Lincoln, 2003b; Kuhn, 1996; Patton, 2002; Peshkin, 1993). Because the area of social entrepreneurship and ID is so under-researched, there is a need for research that is exploratory in nature, not generalizable. Further, generalizability is limited in studying a heterogeneous population such as entrepreneurs (Alvarez & Busenitz, 2001; Gartner, 1988) and people with ID (J. C. Harris, 2006). The current research used a qualitative approach, dyadic interviewing, in order to explore the question of how people with ID are participating and supported in social entrepreneurship with regards to why they act, how they act, and what happens when they act.

D. Use of an Interview Approach

The use of a qualitative interview approach provides flexibility to accommodate for diversity, such as the diversity found among social entrepreneurial ventures and the individuals involved in those ventures. Further, interviews permit tailoring questions to specific situations, asking clarifying questions, and probing for appropriate and relevant exploratory information. The use of probing questions allows an interviewer to “elucidate and illuminate that particular subject” (Patton, 2002, p. 343). In arguing for the further inclusion of perspectives of individuals with ID in research by using qualitative methods such as interviews, Mactavish and colleagues (2000) identified three main strategies in existing research for addressing concerns regarding reliability and validity not just of the participants’ responses, but also of the researchers’ interpretations. These strategies begin with a presumption of credibility, which says there is inherent value in understanding and learning from all perspectives on an issue, including those who may be seen as not having much to offer (Mactavish et al., 2000). This calls for researchers
to be willing to accommodate and adapt so as to enable meaningful participation, including modifying data collection procedures where necessary. Secondly, employing multiple and intensive data collection strategies helps in translating this presumption of credibility into the collection of meaningful data. Finally, concrete data collection strategies may be more effective for qualitative research involving people with ID and can be facilitated by using a structured interview guide (Appendix A) (Mactavish et al., 2000).

Prosser and Bromley provide several techniques to ensure a successful interview in research involving individuals with ID that has been categorized to take into consideration the venue, opening the interview, question style, and question format (Perry, 2008; Prosser & Bromley, 1998). It is important to choose an accessible and convenient venue that is private and free from distraction or interruption. As regards opening the interview, the researcher should take time to build rapport and trust by not jumping immediately into the interview. In the current research, this was accomplished by asking the participants to tell the interviewer “a little about their business.” This question evoked a sense of excitement as participants began to open up, eager to talk about their business and share samples of their work. Additionally, spreading the interview over two or more sessions can serve to relieve pressure on both the interviewer and interviewee and reduce participant fatigue. The structure of dyadic interviewing took this into account by providing for two sequential interviews with participants with ID. Multiple interviews with the same person can approach internal validity by providing for consistency over time (Perry, 2008) and allow opportunity to ask additional questions and gain corrective feedback (Reinharz & Davidman, 1992). The pre-interview period can be used effectively to address both the need to build rapport and trust and to take steps to ensure informed participation. For instance in the current research, the process of recruitment and informed
consent were used as opportunities for the researcher to introduce themselves, to discuss the project in more detail (i.e., what the purpose is and what kinds of questions are likely to be asked), and to discuss any concerns or questions that participants may have. It can also be helpful to explain to participants that there are no “wrong” answers (Perry, 2008). During the interviews with participants with ID, some expressed concern about knowing the “right” answer. To this, the interviewer clarified that they just wanted to know what the participants thought or how they felt about the topic at hand. Occasionally it was helpful to explain analogously that the interview was not a test, in that there were no right or wrong answers.

1. **Ability to consent**

   Regarding the ability of people with ID to consent to participation in qualitative interviewing, one study found that of the forty participants with ID, the majority appeared to understand the nature of the research they were consenting to. However, participants displayed limited understanding in two areas: understanding the risks and benefits of the research as well as understanding their right to refuse to participate or drop out of the study (Arscott, Dagnan, & Kroese, 1998). While this raises significant ethical issues about the protection of these individuals as a vulnerable population, it is important not to allow these difficulties to contribute to the exclusion of people with ID from participation in research. Moreover, doing so would mean excluding people with ID from having the right to volunteer and to have their voices represented in research that can influence the development of policies and practices that will impact their lives. Steps should be taken to accommodate for differences in comprehension and memory (Arscott et al., 1998). For instance, recruitment materials provided in an accessible, plain language format; as simple and straightforward as possible (Appendix B). If a participant is unable to read or write, information may be presented verbally. Participants should have the
option and opportunity to ask questions and the researcher may also ask questions to confirm whether the information has been understood before consent or assent is given (Perry, 2008). As described in greater depth later, for the purposes of this research, participants were provided with a plain language consent form and verbal assent was given before beginning each interview session.

2. **Semi-structured interview guide approach**

In conducting research with individuals with ID the question style should be short, simple, and unambiguous. Prosser and Bromley (1998) developed ten guidelines for simplifying questioning to facilitate research in this vein: use short words and sentences, simplifying sentences; use single-clause sentences; use active verbs; when possible, use the present tense; avoid questions about abstract concepts; avoid double negatives; avoid jargon; avoid figurative language; avoid colloquialisms; prepare questions in advance and assess readability of written questionnaires. However, it is important that these guidelines be contextualized within what has been previously argued about the importance of remaining flexible and willing to accommodate by presenting questions in different formats and trying different wordings at different points during the interview. While closed question formats tend to result in a higher response rate (Sigelman, Budd, Winer, Schoenrock, & Martin, 1982), they are prone to response bias (Finlay & Lyons, 2001; Perry, 2008). Further, multiple-choice and dichotomous questions have been shown to be less reliable than open-ended questions (Malik, Ashton-Shaeffer, & Kleiber, 1991). The current research employed a conversational style of interviewing that used open-ended questions to engage participants.

Qualitative approaches to interviewing vary in both the wording and the sequencing of questions as well as the extent to which questions are predefined. The use of an open-ended
questioning technique is integral to all qualitative interview approaches (Patton, 2002). Open-ended questions allow participants to share their personal perspective by responding to questions in their own words (Patton, 2002). The benefits of qualitative interviewing, using an open question format to minimize the threat of a researcher-imposed agenda, is that it allows relevant issues to be further explored in depth and increases the likelihood that appropriate vocabulary will be used. The disadvantages of this method include a possible decrease in responsiveness, which has been found to vary as a function of participants’ IQ and how questions are framed (Perry, 2008). Finally, this method is more time consuming and responses may be more difficult to interpret and analyze (Denzin & Lincoln, 2003a; Patton, 2002; Perry, 2008).

The primary advantage of an semi-structured interview guide approach is that it allows the interviewer to maintain a conversational style while ensuring that specific topics/subject areas are addressed; retaining a focus on predetermined topics/subject areas and thereby helping to structure the interview and to make this approach systematic and comprehensive across multiple interviews while retaining a necessary degree of flexibility (Patton, 2002). Semi-structured interview guides, such as those used for this research (Appendix A), list issues and questions that a researcher can explore during the course of the interview. Further, a semi-structured interview guide can include more or less detail depending upon how much the interviewer knows in advance and their ability to ask specific questions (Patton, 2002); making it a constructive tool for research on exploratory topics that are under-researched and need further development. The guides used to interview participants with ID and their key support persons were semi-structured around the topics of motivation (why do they act), management (how do they act), and outcomes (what happens when they act) to understand how people with ID are participating and supported in social entrepreneurship.
3. **Acquiescence and response bias**

While qualitative methodologists have problematized the constructs of reliability and validity, they remain fundamental to conducting empirical qualitative research (Denzin & Lincoln, 2003b; Kirk & Miller, 1986; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Patton, 2002). Strategies of trustworthiness have developed in response to ensure rigor that differentiate and expand upon how reliability and validity have been approached within a reductionist, rationalistic quantitative paradigm. While some scholars understandably prefer to use terminology that reinforces this distinction, Morse and colleagues (2002) argue that using the terminology of reliability and validity is important for researchers who need for their work to translate across mainstream scientific fields, policy, and practice; such as the interdisciplinary field of intellectual disability research.

Concerns about validity and reliability continually arise in ID research regarding questions of competence and intellectual capacity, in that the responses of people with ID may not be reliable or valid due to their intellectual impairment and perceptions regarding competency and intellectual capacity. However, if we are to truly value the perspectives and involvement of people with ID in research then we must address these concerns responsibly, in a way that recognizes the presumption of credibility and that does not devalue and further marginalize this group. Critical Theory therefore becomes an invaluable tool in situating reliability and validity, rather than being positioned as antithetical to it.

For example, the incidence of acquiescence and response bias in studies involving people with ID can pose a particular obstacle to the researcher trying to achieve reliability and validity (Dattilo, Hoge, & Malley, 1996; Finlay & Lyons, 2001; Goodley & Rapley, 2002; Mactavish et al., 2000). Response bias refers to incidences when a participant responds to questions according
to how they think the interviewer wants them to answer rather than their response being a reflection of their personal beliefs and experience. For this reason it is important that the researcher make a concerted effort not to ask leading questions or to imply that there is a “right” or a “wrong” answer. Acquiescence bias, or yea-saying, is a type of response bias and refers to incidences when a participant responds affirmatively to questions; not necessarily representative of their true beliefs (Finlay & Lyons, 2001).

Finlay and Lyons (2001) compiled a list of several causes of acquiescence that can serve as an invaluable tool for researchers in constructing interview guides. Researchers should be informed about acquiescence and take into consideration the possibility that research participants may exhibit submissiveness, suggestibility, or have difficulty in understanding the content of the questions being asked or the way in which they are being asked. In conducting research with individuals with ID, it helps if questions can be rephrased and introduced, or reintroduced, at different points during the interview to reduce response and acquiescence bias and to increase internal validity (Dattilo et al., 1996; Mactavish et al., 2000; Malik et al., 1991). Further, utilizing different types of questions can help the researcher identify potential sites of acquiescence to take into consideration during data collection and analysis (Dattilo et al., 1996).

Goodley and Rapley (2002) offer a supplementary argument intended to critically question explanations of participant acquiescence that can be perceived as placing the burden of acquiescence on the individual with ID rather than attributing it to the researcher themselves. In some cases, it may be the reluctance of the interviewer to recognize and accept the answer being given or their inability to understand the given response in context. In this way, the researcher may be subject to or contribute to the social construction of intellectual disability and thereby become a vehicle for the production of acquiescence bias. Accordingly, while research
involving people with ID must begin with a presumption of credibility, it also requires considerable reflexivity (Patton, 2002):

Starting with a presumption of credibility, therefore, is not enough. Researchers must engage in ongoing reflection to ensure that participation is not limited by well-intentioned but potentially misguided assumptions about what people may or may not comprehend. Furthermore, an assumption of credibility must be reflected in data-collection strategies that incorporate the supports required to maximize meaningful participation. (Mactavish et al., 2000, p. 225)

Researcher reflexivity is necessary to ensure that this credibility is upheld (Goodley, 1999; Patton, 2002). While reflexivity can be used as a strategy to resist Othering in academic writing (Krumer-Nevo & Sidi, 2012), it is important to be further aware that in research with individuals with ID accommodations need to be made in order to facilitate equal opportunity and access to research participation within the social relations of research production (McDonald, 2012). It is vital that qualitative researchers in this area recognize the need for methods that integrate techniques promoting interdependence and support and that there be a methodology available that reflects this priority. Dyadic interviewing aims to provide the current research with a structure to help accomplish this purpose.

E. **Dyadic Interviewing**

The use of a dyadic approach is considered a method of triangulation (Eisikovits & Koren, 2010; S. M. Morris, 2001), but it can also be thought of as an accommodation. Although often not explicitly stated this way, the use of joint interviews with family or staff is already prevalent in existing research on ID and employment. Of the eight qualitative studies found that address employment and ID, all of them employed interviewing as a technique. Two interviewed just the individual with ID, whereas seven also interviewed family or staff (Butcher & Wilton, 2008; Carrier, 2007; Devlieger & Trach, 1999; Eisenman, 2007; Hagner & Davies, 2002; A. C. Hall & Kramer, 2009; Jahoda et al., 2009; Lysaght et al., 2009b). Typically the
latter was explained as a way to supplement data gained from the individual with ID and effort made to retain focus on that person as the primary interviewee while the others were secondary or confirmatory sources of information. However, the suggestion of joint interviews is inherently problematic from a Critical Disability Studies approach as concerns the potential for proxy or facilitated responses to suppress the voices of people with ID (Antaki, Finlay, & Walton, 2007; Goodley, 1997; Goodley & Rapley, 2002; Myers, Ager, Kerr, & Myles, 1998; Rodgers, 1999; Stancliffe, Aber, Springborg, & Elkin, 2000). Where this research differs critically, from ID research that has been done with dyads but not under the auspices of dyadic research, is in how the secondary interviewee is chosen and the purpose of their involvement. The inclusion of a key support person in dyadic interviewing is intended to recognize the construct of interdependence and the role that it plays in independence and social participation for people with disabilities (Lloyd, 2001; Reindal, 1999; Tregaskis & Goodley, 2005; Wendell, 1996; G. W. White, Lloyd Simpson, Gonda, Ravesloot, & Coble, 2010).

Dyadic interviewing is still a developing methodological approach; however, its’ strength lies in recognizing the interdependent nature of human agency (Bandura, 2000, 2001). This sentiment is echoed strongly in literature on ID, which recognizes the importance of support in achieving self-determination (Robertson, Emerson, Hatton et al., 2001; Stancliffe, 2001; Wehmeyer, 2001; Wehmeyer & Bolding, 2001; Wehmeyer et al., 2009) and disability scholars who have challenged the ideology of independence (Barton, 1989; Kittay, 2011; J. Morris, 1998, 2001, 2004; Reindal, 1999; Swain, Finkelstein, French, & Oliver, 2004). For people with disabilities, independence refers not to a set of skills or being able to care for one’s self, as professionals tend to define it, but rather it refers to having control over making decisions that directly affect one’s life. It is interesting to note that part of the reason dyadic interviewing
developed as a methodology for studies on couple relationships was because researchers recognized that while the partner may not have been physically present during the interview; they were still a presence during the interview (Boeije, 2004; S. M. Morris, 2001; Seymour, Dix, & Eardley, 1995; Taietz, 1962). Therefore, including the key support person is intended to recognize the construct of interdependence and the role that it plays in independence and social participation for people with disabilities (Lloyd, 2001; Reindal, 1999; Tregaskis & Goodley, 2005; Wendell, 1996; G. W. White et al., 2010).

Dyadic interviews can be conducted separately, jointly, or in combination with each other and have largely been used to study relationships between people with dementia and their carers (Forbat, 2003; Hellstrom, Nolan, & Lundh, 2005; Svanstrom & Dahlberg, 2004) and couplehood relationships (Allan, 1980; S. M. Morris, 2001; Ross & Holmberg, 1992; Veroff, Sutherland, Chadiha, & Ortega, 1993).

Figure 3: Possible Dyadic Interview Combinations
Separate interviews enable each individual to respond from their own perspective; “capturing the individual within the dyad, without forgoing the dyadic perspective” (Eisikovits & Koren, 2010, p. 1643). Whereas conducting interviews jointly results in a shared narrative (Arskey, 1996). This approach has been effective in observing interaction between couples (Allan, 1980), “asking them to represent themselves not just as individuals but also as concurrent participants in a relationship; mutually created meaning is highlighted as they speak” (S. M. Morris, 2001, p. 558). However, this runs the risk of generating acquiescence bias, particularly in the context of dyads involving one member with ID where power is not distributed equally (Antaki et al., 2007; Goodley, 2005; Goodley & Rapley, 2002; Jingree, Finlay, & Antaki, 2006; Peter, 2000; Phillips, 2007; S. A. Thompson, 2003). Further, using a shared narrative approach risks overpowering the voice of those individuals with ID involved. It is for this reason that it is crucial from a Critical Disability Studies perspective that precedence is given to the responses of participants with ID as the unit of analysis rather than dyad itself. Accordingly, weight must be given to the social entrepreneur with ID as the primary source of information and unit of analysis (Patton, 2002). The data collected from the key support person functions as a secondary source that parallels their supportive role.

Utilizing a dyadic approach will allow for comparisons, cross-checking, and triangulation (S. M. Morris, 2001); however, there remain concerns over respondents speaking for people with ID rather than allowing them to speak for themselves. By asking participants with ID to identify the key support person, that is the person they feel most important in supporting their entrepreneurship, this removes an element of paternalism on the part of the researcher and facilitates the role of those individuals with ID in the research as having choice and a voice in how they are represented. The role of the key support person as part of this research is similarly
supportive – mirroring their social role. It is central that the social entrepreneur with intellectual disability choose the person who is representing them, much in the same way an officer of a corporation (e.g., a CEO, CFO, COO, board of directors, etc.) has the ability to assign which individual or entity can represent the corporation (ABA, 2008). This adaptation is a technique intended to impute deference and respect (Goffman, 1982) towards the individuals with ID as business persons and to neutralize the power dynamics at play in research interactions. Further, when conducting face-to-face interviews the researcher dressed professionally in the same manner as when conducting field work with business-owners and experts working in the field as part of the larger research project (PTI).

While the dyadic interviewing technique has been developed for use among populations with ID, the possible applications extend beyond this immediate scope. Dyadic interviewing, as explained here, can be used to interview other groups with developmental or cognitive impairments such as Autism, Asperger’s, Traumatic Brain Injury, Alzheimer’s, and various forms of dementia. Further, there is potential for it to be used in some cases of mental illness or psychiatric disability where there have been episodes of dissociation or where the tenuous concept of one’s “competency” has been questioned.

It is possible that in some cases dyadic interviewing may result in more discrepancies than agreement between participants. However, this should not be assumed to be a failure of the method, but rather indicative of success. If the researcher enters into dyadic interviewing expecting agreement and corroboration then they are introducing researcher bias. Points of disagreement between dyad participants are valuable and rich sources of information, limited only by the researchers’ ability to interpret them. For instance, consider that Finlay and Lyons (2005) found in their research that among thirty-six individuals identified by staff and service
providers as having ID interviewed, only eight people identified unquestionably as having ID. This discrepancy was found to be a rich source of information about how people with ID view their own identity, the social categorization of their impairment, and the stigma attendant. In this vein, elements of researcher reflexivity and reciprocity are essential to the dyadic approach. They impute a sense of deference and respect that does not assume the interviewer knows more than the participants by ascribing preconceived expectations about the relationship between the dyad and the types for responses that should be given rather than interpreting and contextualizing those that are given.

This research used a dyadic interviewing technique to conduct in-depth interviews with social entrepreneurs with ID wherein participants were interviewed separately in three stages: 1) an interview with the social entrepreneur with ID; 2) an interview with the person identified as the key support; and 3) a second interview with the social entrepreneur with ID.

1. **Building rapport and trust**

   In qualitative research, building rapport and trust is essential to gaining entry to conduct fieldwork and enhances the trustworthiness of the data (Mactavish et al., 2000; Patton, 2002). This involves negotiating with gatekeepers as well as gaining physical access to begin collecting data (Nicholson, Colyer, & Cooper, 2012; Patton, 2002). It is not uncommon for researchers to encounter difficulty when trying to conduct an interview with someone with ID wherein a parent, guardian, or staff member wants to remain present during the interview. This presents a dilemma to researchers who are concerned with issues that may arise regarding confidentiality, bias, and proxy responding. For instance, the presence of family or a staff member can affect the way that a participant relates to the interviewer, the rapport they have built, and may engender acquiescence or response bias by introducing external power dynamics.
into the interaction between interviewer and interviewee. Further, the participant may not feel comfortable disclosing certain information when that other person is present because, while their responses will remain confidential and anonymous from that point forward, they are no longer so when another person is present during the interview itself. An interview can therefore be a difficult scenario for researchers to navigate. An interview can therefore be a difficult and ethically challenging scenario for researchers to navigate (for a discussion, Aman & Handen, 2006; Iacono, 2006a, 2006b; McVilly & Dalton, 2006; Ramcharan, 2006).

Yet, successful recruitment of participants with ID frequently involves support persons that act as intermediaries and who may be suspicious or cautious about research participation; likely because that is part of their role in the dyadic relationship. Accordingly, motivators for research participation are needed both for people with ID as well as for their support persons (Nicholson et al., 2012). Using dyad interviews as an interview technique helps to negotiate the interaction in a way that is beneficial to all parties involved: the person with ID, the support person, and the researcher. This technique builds trust and rapport with the support person, thereby affording the researcher to get their foot-in-the-door and begin cultivating a relationship, building trust and rapport with the individual with ID themselves. Dyadic interviewing accomplishes this by providing a structure that recognizes the respective roles of participants with ID as well as their supports while retaining a reasonable amount of flexibility as regards the development of the interview guide and how to best obtain information to address the research questions.

Having structure helps researchers in clearly communicating expectations about participation and thereby addressing some of the intermediaries’ concerns and providing a space for dialogue about other concerns that may be impeding recruitment and participation. Further, it
does so in a way that is proactive and anticipates interdependence rather than attempting to control for or disregard it, which may weaken ecological validity (Brewer, 2000). In summation, the structure of the dyadic interview technique communicates to support persons that they will have an opportunity to give input, to be included, and to contribute meaningfully to the conversation. It gave key support persons a supportive role while still retaining a central focus on the individual with ID. Moreover, multiple interviews allowed time to build trust while also demonstrating that the researcher was interested and invested in understanding the experiences of individuals with disabilities holistically. This parallels the findings of prior ID qualitative research methodologists (Taylor & Bogdan, 1998).

Additionally, the structure of dyadic interviews facilitated the participation of individuals with ID, who did not feel overly pressured to answer questions “correctly” during the first interview. Participants were aware that they could ask the interviewer to follow up with or defer to their key support person on questions they did not feel confident in answering. This defines a space for choice and self-determination in the research process actively, as the interview progresses, as well as structurally as the individual with ID chooses the key support person that will be facilitating. In these instances, any information obtained from the key support person was corroborated during the third interview with the social entrepreneur with ID. Further, because they were going to be interviewed a second time there seemed to be less pressure for participants with ID to try and come up with what they felt was the “right” or perfect answer to a question. Subsequently, the dyadic interview technique has potential to be implemented as an interdependent method of accommodation for people with ID. Taking steps to make accommodations for people with ID contributes significantly towards building rapport and trust because it communicates that the research is invested in understanding what they have to say and
considers it important enough to make an effort to accommodate for impairments and enable equal participation. This dyadic interviewing technique ensures that such accommodations are integral to the research design.

The current research needed to address building rapport and trust along two dimensions: recognizing the participant not simply as an individual with ID, but also as a social entrepreneur. Trust-related issues are a growing area of entrepreneurship research conceptually, empirically (Welter & Smallbone, 2006), and as regards researcher interactions (Neergaard & Ulhoi, 2007). People are protective of their businesses and building rapport and trust is essential to trustworthiness in terms of gaining access to information, but also in gaining accurate and complete information (Neergaard & Ulhoi, 2007). For potential participants and gatekeepers this aspect can introduce additional concerns that the research may impact the services and supports that the business relies upon either positively or negatively. It is important researchers be clear in informing potential participants and gatekeepers about what the research does and does not do; the potential risks and benefits. Potential participants and gatekeepers may need more detailed information regarding how responses will remain confidential, which can include assurances that the information gained through these interviews will not be shared with government institutions, service provider agencies, and business competitors. However, it is also important to ensure that potential participants and gatekeepers do not overestimate the benefits they may receive from such research. For example, this research does not provide technical assistance or consultation services. The only direct benefit for the business is that through these conversational interviews participants may gain additional insight through self-reflection. Indeed, many did. Some took notes for themselves and were generating ideas during the interview. This is a phenomenon that
was also observed during focus groups conducted with social entrepreneurs with disabilities as part of the larger research project (PTI).

2. **Considering joint dyadic interviewing**

Dyadic interviews can also be conducted where the unit of analysis is not the individual with ID alone, but rather the dyad itself. This would deviate from the technique outlined above in two significant ways. First, it would benefit from using a joint interview approach rather than a separate one, which changes the structure of the interviews. Second, it would require observation of the way the dyad interacts during the joint interview. The figure below outlines the four joint interview structures possible. The technique used should be driven by the research question, choosing an interview structure that would be most effective in addressing the question and ensuring that the unit of analysis is appropriate for that question.

It is critical to recognize that the unit of analysis in joint dyadic interviewing is the dyad itself, not the individual with ID, which is reflected in both the analysis and findings. However, this technique is outside the scope of the current research and requires further critical inquiry to 1) ensure that participants with ID are given equal voice and to 2) determine how the key support person is contextualized as they are no longer providing just supportive, secondary information, but rather they are now one of the primary sources. At this point, while joint dyadic interviewing is interdependent, it is unclear the extent to which it can be informed by a Critical Disability Studies ideology; the key difference being the centrality of the person with a disability.
F. **Participants**

Fourteen interviews were conducted in total with seven dyads. This included seven working-age adults with mild to moderate levels of ID engaged in social entrepreneurship and seven individuals identified as the key support person. Purposive, criterion sampling was used to obtain information-rich cases that meet certain criteria (Patton, 2002), detailed below, to ensure that participants self-identified as having an intellectual disability and as social entrepreneurs. The initial recruitment targeted individuals with ID who were social entrepreneurs themselves, which resulted in four participants who had started their own social enterprise and their key support persons. After the completion of these initial four interviews it became apparent that, due to the paucity of research in this area, there was a lack of context for understanding the
experiences of social entrepreneurs with ID and how it differs from the experiences of people with ID who are participating in social entrepreneurship, but not as social entrepreneurs themselves. Accordingly, additional recruitment identified three individuals working at a local social enterprise that employs people with ID, a greenhouse that has been given the pseudonym of Budding Futures, and their key support persons. During data collection, two of the participants with ID working at Budding Futures revealed that they were in the beginning stages of starting a business, providing further context for understanding the experiences of people with ID who choose to pursue social entrepreneurship. As a result, the total participant population includes the experiences of four social entrepreneurs with ID, three people with ID working in a social enterprise, two entrepreneurs in the start-up phase of their business, and their respective key support persons. Chapter III provides rich descriptions of these participants to situate and inform the interpretive analysis that follows.

All participants in this research have been assigned pseudonyms to protect their anonymity. Pseudonyms were created using a website (http://www.fakenamegenerator.com/) that generates a random name based on input to control for gender (male/female) and country (United States). To ensure anonymity, random names were generated for each participant that: 1) were not the same as any of the participants’ names; 2) do not start with the same first letter as the participants’ real name; and 3) matched the participants’ stated gender identification.

1. **Participant demographics**

   Demographics and background information were obtained. For participants with ID, this data included age, race/ethnicity, other employment, and living arrangement (Table II). For key support persons, this data included age, race/ethnicity, their relationship to the participant with ID, their position/title, and other employment (Table III). The average age of
participants with ID was 24 years old, ranging from 19 to 40 years of age. Six of the seven participants with ID had other work, four in paid positions (although not salaried) and two in unpaid/volunteer positions.

### TABLE II

**DEMOGRAPHICS OF PARTICIPANTS WITH ID**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Business</th>
<th>Other Work</th>
<th>Age</th>
<th>Race/Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Nathan</td>
<td>Fair Trade, Organic Coffee</td>
<td>Artist</td>
<td>40</td>
<td>Caucasian</td>
</tr>
<tr>
<td>2. Derek</td>
<td>Fair Trade, Organic Coffee</td>
<td></td>
<td>29</td>
<td>Multiracial</td>
</tr>
<tr>
<td>3. Heather</td>
<td>Public Speaker and Consulting</td>
<td>Clinic Intern</td>
<td>25</td>
<td>Caucasian</td>
</tr>
<tr>
<td>4. Julie</td>
<td>Public Speaker and Jewelry Design</td>
<td>Student</td>
<td>20</td>
<td>Korean</td>
</tr>
<tr>
<td>5. Andrew</td>
<td>Greenhouse</td>
<td>Community College Janitor</td>
<td>24</td>
<td>Multiracial</td>
</tr>
<tr>
<td>6. Kimberly</td>
<td>Greenhouse and Baked Goods Start-Up</td>
<td>Goodwill</td>
<td>19</td>
<td>Caucasian</td>
</tr>
<tr>
<td>7. Wayne</td>
<td>Greenhouse and Baked Goods Start-Up</td>
<td>2 Volunteer Jobs</td>
<td>20</td>
<td>Caucasian</td>
</tr>
</tbody>
</table>

| Average Age | 25 |

Six of the seven participants lived at home with their family, one of whom (Derek) also lived in a small group home part of the time. Only one of the participants (Nathan) lived on their own in an independent living arrangement at the time of the research. Four of the participants with ID were Caucasian, one Korean, and two were multiracial. Finally, two of the participants with ID had been adopted (Julie and Derek).

The average age of key support persons was 49 years old, ranging from 24 to 61 years of age. Six of the seven key support persons were related to the participant with ID, five of those were parents and one (the youngest, Charlie) was a cousin.
TABLE III
DEMOGRAPHICS OF KEY SUPPORT PERSONS

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Position/Title</th>
<th>Relationship</th>
<th>Other Work</th>
<th>Age</th>
<th>Race/Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>James</td>
<td>Job Coach</td>
<td>Job Coach</td>
<td>Yes</td>
<td>40</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Charlie</td>
<td>Co-Manager</td>
<td>Cousin</td>
<td></td>
<td>24</td>
<td>Multiracial</td>
</tr>
<tr>
<td>Mary</td>
<td>Partner</td>
<td>Mother</td>
<td></td>
<td>59</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Lisa</td>
<td>Empowerer</td>
<td>Mother</td>
<td>Yes</td>
<td>52</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Sylvia</td>
<td>Job Coach/Volunteer</td>
<td>Mother</td>
<td></td>
<td>58</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Deborah</td>
<td>Job Coach/Volunteer</td>
<td>Mother</td>
<td>Yes</td>
<td>52</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Bill</td>
<td>Job Coach/Volunteer</td>
<td>Father</td>
<td>Yes</td>
<td>61</td>
<td>Caucasian</td>
</tr>
</tbody>
</table>

Average Age 49

The majority of key support participants were Caucasian, with only one identifying as multiracial and, like his cousin Derek, Charlie was also adopted. At the time of this research, four of the seven key support persons had other employment in addition to the support they provided the participant with ID. For two of the key support persons, Charlie and Mary, their work as part of the social enterprise was also their primary source of employment. When asked to give themselves a title/position that explained their support role, the key support persons working at Budding Futures referred to their formal role as “job coach and volunteer,” whereas key support persons working with social entrepreneurs with ID referred to their role in more descriptive terms as co-manager, business partner, and “empowerer.” However, one of the key support persons referred to his position/title by their formal role as a job coach.

G. Research Design and Procedures

1. Participant recruitment

A targeted recruitment strategy was used for this research and began by identifying service provider agencies and community organizations that serve people with ID in
Illinois. A specific contact person was identified at each organization whose role involved employment services and/or community outreach. Progress was tracked using a Microsoft Excel spreadsheet. An initial email was sent that included the recruitment materials as attachments as well as hyperlinks to where the recruitment materials were hosted online. These recruitment materials included an image-based flier and an accessible version of the flier in a word document (Appendix B). The text of the initial email introduced the project and asked if they would be willing to share information about this research opportunity with any individuals, mailing lists, or organizations that may be appropriate. The email was followed by a phone call in the few instances where the individual working at those organizations did not respond. Often the individual contacted responded to the initial email by calling the contact number listed to discuss the project, gain more information, ask questions, and share their interest in the topic area.

The second phase of recruitment relied upon a snowball sampling technique; distributing emails containing the recruitment materials directly to listservs and mailing lists that are active in the local disability community, such as the Illinois University Center for Excellence in Developmental Disabilities Education (UCEDD) among others:

- Access Living
- Arc of Illinois
- Aspire of Illinois
- Center for Independent Futures
- Chicago ARC/Envision
- Community Choices, Inc.
- Department of Human Services
- Easter Seals
- El Valor
- Family Support Network
- Health and Disability Advocates, Self-Employment Resource Network
- Illinois Association of Microboards and Cooperatives
- Illinois Statewide Advisory Council on Developmental Disabilities
- Illinois Council on Developmental Disabilities
- Illinois Lifespan Network
- Illinois Parents of Adults with Developmental Disabilities, Unite!
- JJs List
- L'Arche
- LifeMyWay
- Neumann Family Services
- Pioneer Center for Human Services
- Progress Center for Independent Living
- Ray Graham Association
- Thresholds Association
- University of Illinois at Chicago, UCEDD
The second phase of recruitment capitalized on both formal networks, as described above, as well as social networking to recruit potential participants. A recruitment announcement was posted on the Facebook Group pages of specific organizations working in the ID field that contained links to where the recruitment materials were being hosted online. This served to generate interest and raise awareness about the research being done. These strategies helped in achieving recruitment saturation and led to several newsletters publishing announcements about the research such as LifeMyWay3, Mainos Memos4, The ARC of Illinois5, and Rush University Medical Center.6 Having organizations that were well respected in the ID community lend their endorsement and support to this research, the “known sponsor approach” (Patton, 2002), helped to begin building trust and rapport with potential participants, families, and staff.

The final phase of recruitment began by contacting the vice president of an organization who had been previously involved with the larger research project (PTI). The organization ran a social enterprise that employed people with ID. Unfortunately, shortly after contact there was a change in management and the organization decided to revert from provision of services using a social enterprise model to their previous sheltered workshop model. The social enterprise still exists and claims to support people with ID from a charity-model approach; however, it no longer employs people with ID. In the wake of this development, an organization that had contacted the researcher during the second phase of recruitment was approached to learn more about their social enterprise and how it employed people with ID. The researcher made a site visit to Budding Futures to observe the work environment, to have an informal interview with the Executive Director, and to speak informally with several of the staff working there both with and

3 http://www.lifemyway.org/ourblog/blogview.asp?blogID=742  
5 http://www.thearcofil.org/arc-and-uic-looking-for-social-entrepreneurs-3  
6 http://www.rush.edu/rumc/print-page-1298329283316.html
without disabilities. Conversation among members of the research team determined that Budding Futures was a good site for exploring the experiences of people with ID involved in social entrepreneurship. Recruitment materials were then distributed to employees, who were asked to contact the researcher if they were interested in participating.

2. **Participant screening and inclusion criteria**

During initial contact, the interview procedure was summarized for potential participants, or the individual who contacted the researcher on their behalf, so that they were aware of what the research was about and of what participation entailed. Potential participants were informed that participation would involve two face-to-face interviews with the individual with ID, each lasting approximately 60 minutes and could be conducted at the time, day, and location of the participants’ choosing. Ideally, the location for the interview was arranged at their place of business so as to allow the researcher to observe the environment within which they worked. In some instances, their workplace was also their residence, family home, or a community organization.

At this point in the screening process it was explained that the individual with ID would be asked in their first interview to identify the person who was most important in supporting their entrepreneurship, a key support person who would also be interviewed. While negotiating this interaction has potential to be uncomfortable or difficult to explain, asking it at this point in the screening process worked well. If asked earlier, it could be overwhelming to people who are considering participating and raise concern over the amount of time it would take. If asked later, it could be misconstrued as being somehow coercive or disingenuous. However, during the screening process there was always a point which the question was asked whether the researcher wanted to talk to someone else (e.g., a family member, staff member, or other support personnel).
or where it was insinuated that the researcher should talk to someone else in order to get what they felt was the information desired. Accordingly, the key support interview acted as a way to diffuse this tension as well as act as an emancipatory technique for involving people with ID in qualitative research. It is interesting to note that the response from the person spoken with during recruitment, if an intermediary and not the individual with ID, was to assume that the key support person would be themselves. While this did tend to be the case, it should not be assumed and, as explained earlier, it is essential that the individual with ID choose who the key support person is without feeling pressured to identify someone they feel they should but who may not necessarily be involved in the business or represent them in the way they would want to be represented.

Potential participants were also informed that they would be receiving thirty dollars to thank them for their participation and as compensation for their time. Both social entrepreneurs and key support persons with ID who participated in interviews were compensated with the same dollar amount. Providing this compensation was important because the time spent participating in the interview was time not being spent working or, for the key support person, supporting the individual with ID in their work. Further, for the larger research project (PTI), social entrepreneurs with disabilities were given compensation of thirty dollars for their participation in the focus groups. Accordingly, it seemed only appropriate that the participants with ID be similarly compensated.

Many of the responses to recruitment that were received were not from social entrepreneurs with ID. For the most part, these were from individuals who had cognitive and psychiatric impairments or other invisible disabilities, for whom the term “intellectual disability” was unclear or who had been referred by a third party. There were a couple of responses from
people with ID who were self-employed or who were undertaking small ventures, such as authoring a book or starting a social group, but who were not social entrepreneurs according to how it has been operationally defined for this research. The screening process described below was instituted to identify which of the potential participants met the inclusion criteria for participation in this research and outlines the operational definitions.

a. **Self-identification of participants with ID**

Participants were asked to self-identify as having mild to moderate ID, meaning that the researcher did not take responsibility for measuring participants’ intellectual impairment in an effort to apply a reductionist label. Rather, participants who identified as having an intellectual disability and/or their intermediaries responded to the recruitment materials by contacting the researcher to indicate their interest in participating in the research. Self-identification can be problematic within the context of ID research because of the heterogeneity of experiences that may be considered intellectual or developmental impairments, particularly given colloquial familiarity with the terminology of “mental retardation” and misunderstanding regarding what ID includes and does not include. However, if individuals facilitating recruitment or potential participants asked for clarification, or if clarification was needed, the AAIDD (2008) definition was provided. If the level of ID (mild-moderate) was unclear, the researcher asked the individual responding to recruitment, typically staff or a family member, if the individual with ID could communicate conversationally and participate in an interview. The interview was explained as a conversation intended to understand and learn about their experiences in starting and running a business. Efforts were made to talk with the potential participant with ID directly before scheduling the interview; however, this was not always possible.
During initial recruitment, participants self-identified as social entrepreneurs. If individuals facilitating recruitment or potential participants asked for clarification, or if clarification was needed, the following criteria was used to determine eligibility for participation: 1) the business was intended to be profit-generating, not just self-sustaining; 2) the business was intended to be growth-oriented; 3) the business had a social mission in addition to a profit-generating one; and 4) the social mission was central to the business. To ensure that potential participants were an integral part of the business the following two questions were asked during screening: who came up with the idea for the business and who runs/manages/owns the business (i.e., whose business is it)? For those who met the criteria for participation, these questions were asked of social entrepreneurs with ID and their key support person in further depth during the interview itself.

The criteria for participants with ID working at Budding Futures differed slightly. Participants were still asked to self-identify as having mild to moderate ID using the same criteria as above. However, their status regarding participation in social entrepreneurship was determined by their involvement with Budding Futures. The criteria enumerated above were used to assess whether Budding Futures was a social enterprise. Questions were asked of participants to gauge their level of involvement and whether or to what extent participants had a role in the idea development, ownership, or management of the business.

b. **Identification of key support participants**

Key support persons were identified by the person with ID. During the first interview, participants with ID were asked to name the one person they felt were most important in supporting their entrepreneurship/work. That individual was sent a recruitment letter (Appendix B) via email and received a phone call to follow up, to address any questions or
concerns, and to schedule the interview. The interview could be done either over the phone or in person, whichever is more convenient, at the day, time, and location of the participants’ choosing.

The person with ID usually wanted to facilitate the researcher in making contact with the key support person; this was viewed as appropriate since the interview did involve them. Typically, they would talk with their key support person following the first interview and that person would then be asked to contact the researcher or know to expect the researcher to contact them via email or phone call. This was very effective, having a retention rate of 100%, particularly given that the key support person was already aware that the individual with ID was being interviewed and that they may be interviewed as well.

3. **Informed consent and assent procedures**

This research was monitored by the University of Illinois at Chicago Office for the Protection of Research Subjects and has been approved by the Institutional Review Board (Protocol # 2010-0536, Appendix C for IRB approval letter). Potential participants with ID that met the inclusion criteria through the screening process were asked for their contact information and were promptly emailed a recruitment letter and an informed consent document written in plain language (Appendix D). All contact information and any identifying information was kept in a secure Microsoft Excel file on the researcher’s computer.

Providing potential participants with a copy of the informed consent in advance allows them to review it, either by themselves or with someone else, and to have the opportunity to address any questions or concerns before they consent to participating in the interview. To ensure that potential participants with ID were fully informed about the research and what participation entailed, a hard copy was also brought to the first interview and was reviewed with
them. Before signing the consent form participants were asked if they understood, if they had any questions or concerns before beginning, and they were assured that participation was voluntary and confidential; if at any point they wanted to stop that would be okay and would in no way affect any of the services or supports that they receive. Following the interview, participants were given a business card with the interviewers’ contact information along with a blank copy of the informed consent for their own safekeeping.

Because the initial informed consent document, signed before the first interview, consents to participation in two interviews, an additional consent document was not necessary to obtain for the subsequent interview. However, the researcher did bring with them a hard copy of the informed consent document to the following interview and reviewed it with the individual with ID before obtaining their assent for participation. Again, they were asked if they understood, if they had any questions or concerns before beginning, and they were assured that participation was voluntary and confidential. Either at or promptly following the conclusion of the last interview the participants were provided with a small envelope containing a card written in simple language thanking them for their participation and a check for thirty dollars.

The informed consent procedure for key support participants is very similar to that of participants with ID. After the first interview, wherein they were identified as the key support person, the potential participants were promptly emailed with a recruitment letter and an informed consent document (Appendix D). In cases where there was not contact information for the key support person, they were asked by the social entrepreneur with ID to make contact with the researcher and were then emailed an electronic copy of the recruitment letter and informed consent document. Prior to conducting the interview, participants were asked if they had a chance to review the consent, if they would like to review it together before beginning, and if
they had any questions or concerns before the interview began. Further, participants were assured that participation was voluntary and confidential. Consent was given verbally and audio recorded before noting it as such on the consent documentation. Following the interview an envelope was promptly given or mailed that contained a note thanking them for their participation and a check for thirty dollars.

4. **Dyadic interviewing procedure**

The dyad technique developed for interviewing individuals with mild to moderate levels of ID for this research involved three stages of interviews (Figure 5). The first stage is conducted with the individual with ID (Pa\(^1\)), the second stage is conducted with the person that they identify as their key support (Pb), and the third stage is conducted with the same individual with ID (Pa\(^2\)) that participated in the first interview. The parenthetical codes refer to how the participant transcripts were both distinguished but also retained their dyadic relationship. The “P” indicates a number that refers to the individual at the center of the interview, the social entrepreneur with ID as the unit of analysis. The pursuant lowercase letter refers to the individual that was interviewed with an “a” representing the person with ID and a “b” representing the key support person. Finally, the number in superscript indicates whether it was the first or second interview with that individual. This coding scheme was effective for internal administrative purposes in maintaining a database of participant information, tracking research expenses, and managing interview audio files and transcripts without sacrificing participant anonymity before pseudonyms were assigned.

a. **Materials**

A semi-structured interview guide was used for each of the interviews, specific to the purpose of that interview (Figure 5 and Appendix A). These provided a flexible
b. **Interview structure**

Interviews were conducted in three stages to allow for comparisons, cross-checking, and triangulation of information. Stage one consists of a preliminary interview with the social entrepreneur with ID to build rapport and trust, to gather background information, and to get a general impression of the entrepreneur’s experience and their supports. During this interview participants with ID identified the key support person who they would like to be interviewed for the second stage of this research. The purpose of the second stage was twofold: 1) to support/complement the first interview, and 2) to inform the third interview. The interview with the key support person serves to provide complementary information and add validity and reliability to the information gained through the first interview. This additional perspective allows for the researcher to gain greater depth of understanding, which facilitates in preparing for the third interview with the social entrepreneur with ID and helps to identify additional topics/questions to pursue and to identify where probe questions may be most effective. However, it is important this interview with the key support person not be viewed as “member checking,” but rather is a method of cross-checking.
The purpose of the third interview was to meet for a second time with the social entrepreneur with ID and, informed by the second interview, to gain a deeper understanding of how they participate and are supported in social entrepreneurship. Similar to the second interview, this also serves as an opportunity to verify the information given by their key support person and strengthen the validity and reliability of the data. Further, the third interview provides an opportunity to incorporate any changes that may have happened to the business over time, since the first interview.

**H. Index Coding and Thematic Analysis**

Coding and analysis in this research focused centrally on the experiences of the participants with ID. Data obtained from the key support person was coded and analyzed as supportive information, giving priority to the data obtained directly from participants with ID.
and bearing in consideration that information from the key support interview was verified during
the final interview with the participant with ID.

The transcripts of interviews were de-identified and imported into qualitative data
management software (ATLAS.ti) for the purposes of coding and data extraction. An “index
coding” approach was used, wherein a set of well-defined codes is produced in advance from
external sources or a quick reading of transcripts (D. Morgan, 2005). A preliminary
comprehensive codebook was drafted based on the literature presented in the previous chapter,
which included sixteen codes. Field notes from participant interviews were used to further refine
the codebook to ten main codes: accommodations, barriers, disability services, entrepreneurship
theory, mission, management, motivation, natural support, outcome, and success/failure
(Appendix E). In index coding, these codes are then applied to segments of text in the
transcripts.

Transcripts were coded separately, starting with the interviews with social entrepreneurs
with ID and their key supports (group 1), before coding the interviews with participants with ID
working at Budding Futures and their key supports (group 2). In both groups, the transcripts of
interviews with participants with ID were coded separately from and in advance of the interview
with their key support person. Transcripts were first coded for data segments corresponding to
entrepreneurship theory and the social mission because essentially that meant verifying that each
unit of analysis met the criteria for inclusion in this research. Next, transcripts were coded for
disability services before coding for barriers and accommodations as that order allowed the
researcher to capture both barriers and accommodation within the context of disability services,
given the extent to which they overlap. Transcripts were then coded for natural supports, which
complement disability services in referring to data segments where family, friends, or friends of
the family provided support to the individual with ID and/or their business. Motivation was coded next; referring to what motivates the individual with ID and not what motivates the business itself or the key support person. Finally, transcripts were coded for outcomes and success/failure, the latter differs from the former in that it referred to data segments containing a more theoretical and conceptual discussion. Whereas the explicit coding of concrete outcomes did not retrieve much data for social entrepreneurs with ID, it retrieved considerably more data for participants with ID working at Budding Futures.

The raw data were extracted to a Microsoft Word file for each code and data from key support persons was color coded to distinguish it from the responses of participants with ID during analysis. This had the effect of highlighting overlaps and contrasts in the process of comparing and triangulating the dyadic data (Eisikovits & Koren, 2010). Thematic analysis was used to categorize and interpret the data within each document. Based upon the findings revealed and the context provided by the thematic data, the documents were then sorted into one of three folders: motivation, management, or outcomes.

<table>
<thead>
<tr>
<th>Motivation</th>
<th>Management</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mission</td>
<td>Accommodation</td>
<td>Entrepreneurship</td>
</tr>
<tr>
<td>Motivation</td>
<td>Barrier</td>
<td>Outcome</td>
</tr>
<tr>
<td></td>
<td>Disability Services</td>
<td>Success/Failure</td>
</tr>
<tr>
<td></td>
<td>Management</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Natural Supports</td>
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</tbody>
</table>
This process resulted in three overarching themes, containing between them the ten themes identified and refined through index coding, each of which contain between two and six sub-themes comprising the bulk of analysis.

The approach taken for reporting was to address the findings revealed through thematic analysis for each of the three overarching themes as a content chapter, drawing upon the interpretation of the data to address the research question at hand. The discussion chapter synthesizes the information presented in previous chapters to problematize the broader research question of “success” in social entrepreneurship and the application of the findings to the fields of disability employment and social entrepreneurship. However, before delving into the analysis, it is crucial to have an appreciation for the participants, their backgrounds, and their businesses.
IV. RICH PARTICIPANT DESCRIPTION

The in-depth interviews yielded rich information about the participants in this research; divulging great insight into the experiences of people with ID involved in social entrepreneurship and their supports. The purpose of providing this information in a chapter separate from the methodology responds to the complexity of conducting qualitative dyadic research in social entrepreneurship. This research necessitates familiarization with not only members of the dyad, but also with their business and the roles of the individual with ID and the key support person within the social enterprise. What follows is a thick description of the participants and their businesses for the purpose of introducing the research participants and providing context necessary to inform the subsequent analysis.

A. **Nathan**

<table>
<thead>
<tr>
<th>Age: 40</th>
<th>Fair Trade, Organic Coffee</th>
<th>Est. 2010</th>
<th>Operational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key Support Person: James, Job Coach</td>
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</tbody>
</table>

Social Mission: “Fair trade is better because it supports families and gives them a better wage where they can live and have a nice home and food on the table. It helps people who know about what other big coffee companies do and they know they are getting coffee that is fair trade and organic so it helps others who care about social justice stuff.” (Nathan)

Nathan had several other jobs before beginning his social enterprise. However, he quickly tired of them as he felt the pace was too fast and the positions too stressful. Then, due to health problems and resulting complications, Nathan had to relocate to be closer to his family and the hospital. This affected the time he could spend working. There were also limited options for work available in the area. Meanwhile, Nathan dreamed of becoming a professional artist or a business owner. His artisanal social enterprise brings these two dreams together; creating unique, organic and ethically sourced coffee flavors that people will enjoy:
Nathan: I love it because I love coffee and its fair trade organic stuff. I like flavored coffee and I thought maybe it was a good idea if I make it a business since I have regular and decaf for all the flavors. If someone requests a flavor that I don’t have, I make it up… I also have dreams about new, different flavors too.

Nathan’s business started as a hobby, giving coffee as gifts to people until a friend suggested he start selling it. While Nathan and his dad tried to legitimize the business when he was living at his parents’ home, it was only when his living and working arrangement changed and allowed him to become more independent that his business came to fruition. Currently, Nathan works with a job coach (James) through his service provider, who is also an entrepreneur, and whom Nathan identified as his key support person. James works as a job coach for a couple of other individuals with ID as well, but none of them are pursing social entrepreneurship.

Nathan’s social enterprise uses fair trade and organic coffee, obtained from an out-of-state distributor certified as Fair Trade USDA Organic. Nathan utilizes a variety of blends from different countries: dark roast, a breakfast blend, and decaffeinated. The coffee comes roasted from the distributor, and where Nathan distinguishes himself is in the flavors he creates and adds to the coffee:

Nathan: My distributor, in the coffee shop itself, they sell their coffee… but I’m helping them in a way because I have flavors and they don’t have flavors. So they don’t mind it. They’re my supplier and I don’t think they want to lose me because they need big customers that order a lot from me.

After he adds the flavoring, Nathan repackages and labels his product. Nathan offers regular as well as seasonal flavors. In addition, Nathan’s flavors come in decaffeinated, which he feels is an area often overlooked. At the time of Nathan’s first interview, he was creating his coffee product in the kitchens where he lived and worked. However, since his first interview, Nathan has been working towards finding a shared-use, commercial kitchen facility where people with small businesses and food trucks can rent space in compliance with city ordinances and sanitation licensing. Orders for Nathan’s products are placed directly via email and are delivered
by Nathan or picked up at his service provider. Eventually, Nathan hopes to offer online ordering for his customers and negotiate a shipping arrangement so he can expand his customer base beyond Chicago.

Currently, Nathan’s customer base comprises individual customers who hear about his product through word of mouth, one of whom buys it to supply a local soup kitchen. Moving forward, Nathan hopes to market his product by reaching out to local small businesses and restaurants, as well as target an affluent tourist destination in a neighboring state where he has a connection through a friend’s parents. However, Nathan is waiting on getting his business license and obtaining space at a shared kitchen before expanding. Down the road, Nathan hopes to have his own facility where he can hire employees and continue making his coffee product.

B. **Derek**

<table>
<thead>
<tr>
<th>Age: 29</th>
<th>Fair Trade, Organic Coffee</th>
<th>Est. 2008</th>
<th>Operational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key Support Person: Charlie, Cousin and Employee</td>
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</table>

Social Mission: [“Better than fair trade”] means that when we buy, we buy directly from the owner of the farm.” (Derek)

“… the fair trade certified has to do with the compensation of the farmers and a lot of time these farmers aren’t compensated. We buy our beans directly from the farmers so I guess that’s what the “better” part means. You’re paying the farmer and it doesn’t go through any kind of middle person.” (Charlie)

Like Nathan, Derek’s enterprise produces a Fair Trade coffee product but, unlike Nathan’s business, Derek’s enterprise focuses on the coffee, itself, rather than the flavors. Derek’s passion for the freshness and quality of the coffee bean, roast, and cupping (a coffee tasting ritual) poses an interesting contrast with his personal tastes: he loves making coffee for others but does not like to drink it himself. Also working for the business as an employee is Derek’s cousin and key support person, Charlie.
Derek’s coffee beans are imported directly from farmers in South America by his uncle, in cooperation with a Fair Trade certified, Chicago-based coffee roasting company (referred to here as “Coffee Co.”). Coffee Co. sells its own blends, but also provides services that include training on how to roast coffee and equipment.

Derek: [Coffee Co.] does the roasting and coffee is actually a green bean. You know where they get the green beans from? Cherries. The coffee plant has cherries and they split the cherry in half and then you get the green bean and then the bean has to go through a process and then it can be drilled…. [Coffee Co.] lets me come down and roast them and bag them and pick them up.

Approximately once a week, or as needed, Derek goes to Coffee Co. to pick up the freshly-roasted beans, which are subsequently packaged and labeled. Derek and Charlie both obtained sanitation licenses that permit them to package the roasted beans at Derek’s family home. At the time of these interviews, Derek’s business had a website where customers could place orders via direct contact (phone or email). However, the website no longer appears to be operational and has since been replaced by social media pages (Facebook, Twitter, etc) and a blog.

The majority of Derek’s customer orders come from personal connections and a regular stand he operates at the local farmers market where customers can place a custom order to be picked up the following week. Derek’s business offers shipping, seasonal packages, gift wrap, and flavored coffee. However, because the flavored coffee costs more to make they tend not to keep a lot of it in stock unless specially ordered. One day, Derek hopes to have his own storefront to make and sell his coffee in, but for now he plans on marketing his product by reaching out to a locally-based grocery store chain that shares the values of freshness and quality to see if they will stock and sell his product.

Derek also had several other jobs before starting his social enterprise. While Derek enjoyed these positions, ultimately they were not a good fit for him. Derek found the work boring, too “shaky,” too slow, and lacking social interaction. According to his cousin, Charlie,
“it’s his social side that got in the way.” Derek wanted to interact with people more than the jobs available would allow. Derek’s desire for social interaction was motivated in part by dissatisfaction with his living arrangement:

Charlie: Derek was in and out of another program. It was an organization that houses people with disabilities, but he wanted to come back home and he needed something to do. This place kind of left him not in a good spot and he wasn’t connecting with people as much as he wanted to. The business was something he wanted to do…

At his uncle’s suggestion, Charlie became Derek’s personal assistant so that Derek could move back home with his family. The change in living arrangement and increased support combined with his uncle’s business connections made the opportunity for Derek to start a business possible. Derek’s current social enterprise was not his first entrepreneurial attempt. It was something that he had dreamt about when he was young:

Derek: I had a dream that I should run a business because at a very young age…. When I was around eight I had an injury. A car hit me… and my sister and I were going to school…. Then she spent one day, twenty-four hours, in the hospital and I spent five months. Then I had a dream…. My aunt was there and she asked me if I’d go and get a button for her and she’d give me a dollar. I brought back more buttons and started selling them.

When asked about being a businessperson, Derek replied lightheartedly, “Some of us are chosen to be who we are and to run a business. It’s no one’s fault for what has happened to anyone.”

C. Heather

<table>
<thead>
<tr>
<th>Age: 25</th>
<th>Public Speaking and Consulting</th>
<th>Est. 2004</th>
<th>Operational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key Support Person, Mary, Mother and Business Partner</td>
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Social Mission: “I want other people to see the kinds of things that I do like students teaching students to be [self-advocates] and how to be inclusive in their own school and community… helping educators, assistant principals, superintendents. Those are the main people who need to be in the school and they hear what I’m saying and change the way their inclusion is…. I want to reach out to more communities and more districts. I want to tell them it’s not just me that’s a [self-advocate] but it’s all others too.” (Heather)
Heather maintains several jobs in addition to her social entrepreneurship and, while she enjoys her other work, she views her business as her profession and her passion. Heather shares partnership in the business with her mother and key support person, Mary. Heather’s aunt, who is a special educator, occasionally works with the business as a consultant. Heather, Mary, and her aunt each contribute a different perspective to the social enterprise based on their individual experiences with inclusive education as a person with ID, as a parent, and as a special educator, respectively.

Mary: … [Heather] has her business and I have mine, but they’re sister businesses. Sometimes we’ll do presentations, but it’s really speaking that is her thing and a little teaching…. Yes [we are business partners], but we keep it separate. We have our own things but they blend.

It is Mary’s policy that if she is invited to speak or give a workshop somewhere to insist that Heather speak as well since this is necessary to their mission of inclusion. Heather and Mary’s business offers services including workshops, public speaking, counseling, and consulting. Heather’s work focuses primarily on public speaking, sharing her story of being a self-advocate in Individualized Education Program (IEP) meetings. With support, Heather prepares her speeches in advance and practices them daily. In addition, Heather provides accessible workshops and counseling on: 1) self-advocacy, self-determination, person-centered planning, and transition planning for young adults with ID; 2) inclusive education workshop training for teachers and school administrators; and 3) disability awareness workshops for students. While the business does not sell any formalized products, Heather and Mary’s workshops promote the tools, models, and methods for adapting curriculum they have developed through a combination of training and personal experience.

Heather’s self-advocacy began early-on when her mother suggested she begin presenting at her own IEP meetings in school. This is significant because often IEP meetings are conducted
to discuss a student’s educational plan without the student being present or giving their input. It was imperative to Mary that Heather’s voice be included in the decision-making process:

Mary: She was on the speech team in high school and everything came together with this at the IEP meeting so she could tell them what her dreams were. She was supposed to be self-contained her whole life with no exposure to general curriculum…. A lot of people are working sheltered workshops and that’s not what we wanted and that’s not the dream. She has specific gifts and we need to use those gifts and help her go forward.

Over time, Heather was increasingly invited to speak about her experience and she became involved with self-advocacy organizations. During transition planning Heather and Mary brainstormed several ideas for work, many of which were self-employment arrangements. Self-employment seemed like a good option because it afforded flexibility in her schedule so that Heather could continue to be involved in other activities. At first Heather and Mary were unsure whether the venture would garner enough interest to be viable. However, the business has since expanded to include work with families in similar situations and inclusive curriculum:

Heather: We’re doing it because some people don’t take curriculum seriously. They need to realize curriculum is more important. I had a lot of good regular education through school but none of the people with disabilities have that established so we want to tell people that here is what I used to help Heather be included…. I can say the governor of Illinois has a chance to hear about my business and what I’m doing and planning to help inclusion, not segregating them. I have a quote “I’m terrified of how different my life would be if I was segregated.” That would have been horrible if I was segregated like in a state institution for example. My family would fight people who would put me in a state institution.

Heather has been invited to speak all over the U.S. and looks forward to an opportunity to speak internationally. Heather’s business is marketed primarily through word of mouth and networking through professional and community organizations: “… [Heather] spoke to one-thousand, two-hundred people and from there she got a job to go speak in a school. Wherever we go, we get more jobs” (Mary).

Heather’s business utilizes brochures maintains a website which provides information on the business, lists the services offered, and hosts videos demonstrating their work:
Heather: My aunt does things on my website about what I’ve done. It tells everybody that a person with [ID] is an advocate for people with disabilities. Having a website is important when starting a business because it helps you grow your business out…. That’s the most important thing because people find information and can email me to ask questions – you need the purpose, the point of view, an attention-getter and the meaning is having a purpose.

The website for Heather’s business provides a contact form and email address which Mary manages. Accordingly, Mary receives requests and contracts for work that are discussed with Heather and they schedule it together. Heather has her own personal website as well that focuses more centrally on her role in the business and her other interests. For instance, she occasionally also speaks on pro-life issues, advocating against the abortion of fetuses with disabilities.

D. **Julie**

<table>
<thead>
<tr>
<th>Age: 20</th>
<th>Public Speaking and Jewelry Design</th>
<th>Est. 2010</th>
<th>Operational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key Support Person: Lisa, Mother</td>
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</table>

Social Mission: “I go out into the community because there are some grade schools that I actually go out to and talk to the class. I say this is my real life and everywhere I go, all I can see is people’s behinds. Nobody ever knows that I’m here with the dog and they don’t realize that they’re actually not thinking. When I’m in a big crowd, they step on the dog and nobody gets to see me… you have to be aware that there’s a person and a dog right where you are…. Yes, and the profit goes to the service dog program… some of the people in our town usually go to the [regional service animal organization] and they can actually log on the website and see what they need.” (Julie)

Julie has two businesses which operate separately but share the same social mission and beneficiary organization: a public speaking business and a jewelry design business, the proceeds from which go to support her local service dog program. When the time came to develop a transition plan for Julie, her mother and key support person, Lisa, was concerned that Julie’s health problems would limit the time she could spend working and the type of work that she could do:

Lisa: We worked with the school on a transition plan for her and we wanted something realistic and built on her strengths. She gets stopped all the time and we couldn’t see why she should be trained for a sheltered workshop based on her size and her nature.
Julie, still in high school, has not had much prior work experience. However, Julie has extensive experience answering the questions people ask her in public about her physical disability and her service animal. Julie enjoys telling her story and answering questions. It was something that she was “already doing anyway” (Lisa) and public speaking was a vehicle she could use to develop soft skills for future employment (Office of Disability Employment Policy, 2011). Julie also began designing jewelry and found that not only does she enjoy “making something and creating something that people don’t have”, but also that people want to buy it. Since, Julie has integrated jewelry design into her business, using it as a tool to raise awareness about service animals.

Julie’s public speaking engagements primarily target students in grade school and high school, although she has spoken before large audiences at national disability organizational meetings. Julie’s speeches are developed in advance, focusing on issues of awareness around her service dog and her experience living as a person with a disability. The presentations are created using PowerPoint and are presented in an interview format, facilitated by Julie’s key support person, Lisa. The interview format is ideal for Julie, who works best when given prompts to respond to. Profit made from Julie’s public speaking engagements goes towards the service dog program. Julie markets her public speaking primarily within school networks, but also utilizes a website, a logo designed by a family member, business cards, and social media pages (Facebook, Flickr, Etsy). Julie’s website includes a contact form where requests for information are managed by her parents. Unfortunately, recent health concerns have prevented Julie from committing to speaking engagements in the near future.

The Facebook page for Julie’s business appears to be the primary vehicle for her jewelry design business. Previously the jewelry business had started as a page on a community non-
profit website that provides free, personalized web pages to people during a health crisis to help friends and family keep in touch. As interest in ordering the jewelry Julie designs grew it became a separate entity. Although, Julie and Lisa are still testing the waters with this business, it appears that jewelry design is something that Julie can continue to work on and enjoy while dealing with her health concerns. Orders for Julie’s jewelry can be placed online through her Etsy shop or through direct communication.

Julie: Yes, they tell them to go to a website and they can order something online or in person. They say I would like this bracelet, but I need it a little bit bigger and then my mom would measure to see how much wire we would need to see.

Uniquely, each piece of Julie’s jewelry includes a dog paw charm to remind customers to donate to their local service animal organization. The profits from Julie’s jewelry business are allocated to pay for additional supplies with the remainder donated to the local service dog program.

E. **Budding Futures**

<table>
<thead>
<tr>
<th>Greenhouse</th>
<th>Est. 2005</th>
<th>Operational</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Team Member:</strong></td>
<td>Andrew, 24 years old</td>
<td><strong>Key Support Person:</strong> Sylvia, Mother</td>
</tr>
<tr>
<td>Kimberly, 19 years old</td>
<td>Deborah, Mother</td>
<td></td>
</tr>
<tr>
<td>Wayne, 20 years old</td>
<td>Bill, Father</td>
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</tr>
</tbody>
</table>

Mission Statement: To provide people with disabilities the opportunity to lead fulfilling lives and to train and work in a supportive, safe and caring environment while producing and providing products and services to the community. In this pursuit, we honor the concepts of human dignity, respect, hard work, fellowship and friendship.

Budding Futures is a social enterprise that was founded in 2005 by a group of parents frustrated with the lack options available for their children with intellectual and developmental disabilities to work, and did not wanting their children to end up in segregated environments with limited opportunities (e.g., sheltered workshops or day programs). Accordingly, Budding Futures does not turn anyone away and is willing to work with people to make accommodations for any disability. Budding Futures is organized as a non-profit greenhouse, which operates as a
retail wholesale business that has an integrated workforce of people with and without disabilities. Employees with disabilities are referred to as “Team Members.” Team Members receive monthly paychecks and are paid an hourly rate at minimum wage.

Working at the greenhouse requires each team member to be accompanied by a job coach. Usually this role is filled by a parent or family member volunteering their time. Occasionally a job coach may be provided through a school vocational program. Team Members are required to pay a fee to participate in the greenhouse, with a minimum of $150 for 10 hours of work per month. Budding Futures provides a limited number of scholarships for families who cannot afford the membership fee. Budding Futures needs to maintain a membership of at least forty families in order to remain operational, but have the capacity to support up to seventy-five families. In 2011, Budding Futures generated $286,224 in revenue with $264,082 in total expenses. It is unclear from their financial statement (IRS Form 990) how much of their expenses were paid to Team Members or how much of their operating costs were funded by membership fees.

Located over five acres in a remote industrial park, the Budding Futures greenhouse is not easily accessible by public transportation. Team Members get transportation to the greenhouse through their school program or their parents. Team Members do not choose what kind of work they do. When they arrive at Budding Futures each day they clock in and check the job board or ask to find out what needs to be done, perform the work they are directed to do, and clock out at the end of their work hours. The tasks for Team Members vary depending upon what needs to be done, but may include work inside or outside depending upon the weather. Inside the greenhouse they may be using the dirt machine, filling pots and trays with soil, planting seeds, deadheading, sweeping, and vacuuming. They may also be working making
crafts or greeting cards, making cement bricks or stepping stones, interacting with customers and operating the cash register, or cleaning the glass in the display cases.

1. **Andrew**

   Andrew was one of the first team members to begin working at Budding Futures when it was founded, having started just before transition when he was sixteen. Andrew works at Budding Futures with his parents and his father is on the organization’s Board of Directors. His mother was identified as Andrew’s key support person, although both of his parents volunteer and often work at Budding Futures together. It is not uncommon for Andrew and his parents to work more than the hours that Andrew is paid for. Andrew tends to work the dirt machine, make bricks, or fill pots because he is more experienced in those tasks than other Team Members. However, his favorite job is sweeping the dirt and debris. Andrew also works as a janitor at a local community college. When asked about where he sees himself in the future, Andrew said he would like to be a professional gardener and has thought about going to college and maybe starting a business.

2. **Kimberly**

   Kimberly started working at Budding Futures four years ago, when she was sixteen. Kimberly began working ten hours per month with her mother and key support person, Deborah, as her job coach. They heard about Budding Futures because Deborah is friends with several of the founding members. Currently, her work at Budding Futures has been integrated as part of Kimberly’s transition plan and she attends with her school program where a job coach is provided by the district. While she likes working at Budding Futures with her friends, Kimberly does not like to get her hands dirty, preferring to work on crafts when possible, but ideally would like to work the cash register. Kimberly also has a job working in a Goodwill store and enjoys
retail, but seldom gets to work the cash register there either. When asked if she had ever considered self-employment, Kimberly revealed that she was in the process of starting a baked goods business with Wayne and three of their friends. This new venture is still in the idea development phase and they have been meeting to brainstorm exactly what they want to do as they are thinking of also doing event planning.

3. **Wayne**

At the time of his first interview, Wayne had been working at Budding Futures for a little over a year. Wayne started working at the greenhouse ten hours per month. During the week Wayne attends with a job coach provided by his school program and his parents volunteer to work as needed. Wayne identified his father, Bill, as his key support person. Wayne likes the variety of tasks at Budding Futures and working with his friends. However, Wayne does not like to get dirty and is not particularly interested in making crafts. He enjoys deadheading plants most because, “It’s the least disgusting job at that place” (Wayne). In addition to being in the start-up development stage of a business with Kimberly and their friends, Wayne has two volunteer positions working at a local grocery store and in the office of the athletics department at a local high school. Wayne enjoys the office job the most and hopes that it will someday become a paid position.

F. **Summary**

These accounts illustrate the varied and creative ways that people with ID are participating in social entrepreneurship, both as social entrepreneurs themselves and working within an existing social enterprise. A Critical Disability Studies approach will explore the experiences of participants with ID first at the individual level, then use this information to situate literature and policy at the structural level, and finally reifying the participants’
experiences within the structural context to understand how individuals with ID are participating and supported in social entrepreneurship within the current socio-political environment.
V. MOTIVATION: “WHY THEY ACT”  

Understanding the concept of motivation as it applies to social entrepreneurship is critical because motivation explores the reasons people with ID get involved in this strategy for employment. By understanding their motivation, we learn what drives people with ID into social entrepreneurship. Motivation from the point of view of people with ID, addresses concerns in the field regarding the potential co-optation of social entrepreneurship, using the term to rebrand or repackage employment practices that are segregated or oppressive, or that social entrepreneurship may be used as a neoliberal strategy to remove responsibility for the provision of employment services from the public to the private domain. Learning how people with ID are participating and supported in their motivation to pursue social entrepreneurship, from their standpoint, provides insight into how choice and self-determination manifest and whether people with ID are choosing to become social entrepreneurs because they really want to. To this end, this chapter explores push-pull factors affecting motivation, the role of the social mission, and how support influences motivation in moving between the individual and the structural.

Push-pull theory is one way of conceptualizing entrepreneurial motivation and served as a helpful cognitive tool for discussing motivation with the participants in this research. Push-pull theory provided an understandable and relatable concept: that someone might choose to pursue entrepreneurship either because of difficulty finding work or a lack of other options (push) or because of an interest or passion (pull) for the work they were doing. Additionally, since the larger research project (PTI) asked focus group and interview participants questions about push and pull motivations, utilizing the same concept provides consistency, allowing for future comparison between groups.

7 This chapter includes information that has been published elsewhere: Parker Harris, S., Caldwell, K., & Renko, M. (in press). Entrepreneurship by Any Other Name: Self-Sufficiency versus Innovation. Journal of Social Work in Disability & Rehabilitation.
A. **Individual**

1. **Motivational factors of social entrepreneurs with ID**

   Both push and pull factors played a role in motivating the social entrepreneurs with ID in starting their businesses, in pursuing a social mission, and in continuing to work on their business. While all four social entrepreneurs interviewed (Nathan, Derek, Heather, and Julie) acknowledged the push factors affecting them, such as the state of the economy and difficulty finding a job, they expressed greater value for the pull factors, such as desire to start a business and passion for their social mission (Table IV).

   Regarding push motivations, Nathan and Derek were both dissatisfied with their previous jobs, which were not a good fit for their skills or interests. One of the central motivating factors for Heather and Julie’s employment was to make the most of their talents and strengths. The pace of work can operate as a barrier to people with ID and thus serve as motivation to pursue social entrepreneurship. For instance, Nathan found the work he was doing too fast and stressful, whereas Derek found it too slow and he felt he was not involved enough. Working on their own businesses allows Nathan and Derek the control and flexibility to work at their own pace. Pace was also a concern for Julie. Her mother believed that Julie’s health problems and physical disability limited the time she could spend working and the type of work that she could do, similar to how health problems had restricted Nathan’s employment in the past. Living arrangement also emerged as an important push factor, with location affecting the type of work available. This research provides a strong indication that living at home with family may provide the support needed to start a social enterprise. However, it bears further consideration what role living arrangement plays in establishing a business. It was only after moving to a more independent living arrangement, a Community Integrated Living Arrangement (CILA), that
### TABLE IV

**MOTIVATIONAL FACTORS OF PARTICIPANTS WITH ID**

<table>
<thead>
<tr>
<th>Social Entrepreneurs with ID (Nathan, Derek, Heather and Julie)</th>
<th>Working at Budding Futures (Kimberly, Andrew and Wayne)</th>
<th>Wanting to start a Business (Kimberly and Wayne)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Push Factors</strong></td>
<td><strong>Push Factors</strong></td>
<td><strong>Push Factors</strong></td>
</tr>
<tr>
<td>• Boredom with other options, lack of interest, don’t like other options</td>
<td>• Hard to find a job, build skills to find another job</td>
<td>• Other work is not matched to interests/talent</td>
</tr>
<tr>
<td>• Productivity, feel time would not be well spent</td>
<td>• Need work credits</td>
<td>• As a side job while look for other work</td>
</tr>
<tr>
<td>• Not a good fit, pace is too fast or too slow, too stressful</td>
<td>• Transition or temporary job, want a new/different/more permanent job</td>
<td>• Lack of choices, don’t want to overlook opportunity to be paid</td>
</tr>
<tr>
<td>• Health problems limit options</td>
<td>• Need/want to make money, not just to volunteer</td>
<td></td>
</tr>
<tr>
<td>• Difficulty finding other jobs due to economy and disability discrimination</td>
<td>• Need to fill up time, want something to do</td>
<td></td>
</tr>
<tr>
<td>• Actual and expected disability discrimination</td>
<td>• Want to change living arrangement, go to college</td>
<td></td>
</tr>
<tr>
<td>• Lack of social interaction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Want to change living arrangement</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Pull Factors</strong></td>
<td><strong>Pull Factors</strong></td>
<td><strong>Pull Factors</strong></td>
</tr>
<tr>
<td>• Dream or desire to start a business</td>
<td>• Have friends working there</td>
<td>• Dream or interest in starting a business</td>
</tr>
<tr>
<td>• Interest and passion for social mission</td>
<td>• Parents want them to, heard about through social network</td>
<td>• Being a boss, running a business</td>
</tr>
<tr>
<td>• It is fun, want to do something they like</td>
<td>• Work is fun and easy</td>
<td>• Working with friends</td>
</tr>
<tr>
<td>• Want to be productive, contribute, to help</td>
<td>• Disability-friendly environment, security and flexibility</td>
<td>• Interacting with customers, like working with people in customer service/retail</td>
</tr>
<tr>
<td>• Born or chosen, have a talent</td>
<td>• Want to do something productive, good work ethic</td>
<td></td>
</tr>
<tr>
<td>• Self-advocacy/advocacy, social responsibility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Had an opportunity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Flexible, not confining or limiting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• To have a “real” job or profession</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Counteract stigma that someone cannot do something because of their disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Social interaction with community, because they like people</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Nathan felt his business became legitimate. Up to that point, Nathan’s business had been only a hobby and not a “real” business. When Julie was asked about what distinguishes her businesses from a hobby she said, “[a] hobby is like I could just do it for fun. A business, we’re trying to run something.”

One of the central pull factors identified by the social entrepreneurs with ID was fulfilling their dream of business ownership and being a professional. While Derek enjoys being the boss, in charge, and in control; he comes alive when talking about his customers and their enjoyment of a quality, ethically-sourced product. Indeed, Derek’s customers’ enjoyment of his product seems to be his chief motivation. Another pull factor identified was the desire to help others, contributing to their social mission:

Julie: When you’re this small and people take you for granted, then you’re stuck. When you see everyone else they’re like oh I didn’t think about that and now this is a chance to do this for you and for some of your friends.

People with ID are often portrayed as recipients of care, in dependent roles that do not recognize their capacity to help or to act as social agents. In this context, it is this very assumption that social entrepreneurship challenges. The social entrepreneurs with ID interviewed in this research got enjoyment and satisfaction out of helping others, expressing a sense of social responsibility:

Heather: I have been blessed with the privilege and use my voice because other people cannot use their voice so I’m here for them.

Indeed, Heather’s primary motivation is to help people who lack the opportunities she had by teaching them to advocate for themselves and equipping them with the tools to help make that possible.

2. **Motivation and social mission**

A key part of each social entrepreneur’s motivation was the social mission of their business itself. Given that social entrepreneurs tend to be inspired by problems or needs they
have experienced and that people with ID experience significant barriers in various areas of life, one might expect the social mission of participants’ businesses to be related to their disability. However, the relationship between social mission and disability appears more complex; there may be multiple social missions for the social entrepreneur with ID, and not all of them directly related to the mission of the business itself. For example, the direct social mission for Nathan and Derek’s businesses relate to fair trade, organic coffee; however, Nathan has an indirect social mission that is motivated by his experience living as a person with ID. Conversely, the direct social mission for Heather and Julie both draw explicitly on their experiences with disability, although not necessarily ID, and it is their indirect social missions that divulge ancillary motivations.

a. **Indirect social mission**

Three of the four social entrepreneurs had indirect social missions. For Nathan, it was important to show to others, with and without disabilities, that someone with an intellectual disability could start a business. This was motivated by a negative experience that he had while in school with a teacher who had discouraged him from trying to follow his dreams.

**Interviewer: Do you like owning your own business?**

Nathan: Yes, I do! I like it because people told me don’t dream dreams so I want to show them that people with disabilities can do what we want. I want people with disabilities to know, especially intellectual disabilities, that if someone tells you don’t do it, you just try… just try.

**Interviewer: So does that motivate you?**

Nathan: Yes. If people tell you because of your disability that you can’t dream dreams, I tell them it’s not true. You just try and try again and if it doesn’t work, then it’s not for you and you try something else. It’s true for all the disabled community and we should have rights because we’re human beings. I’m seeing a big change now because back in the day they said if you had Down Syndrome you had to be given away or if you had my disability, you had to be locked away.
Nathan’s fear of segregation and institutionalization was similar to a sentiment expressed by Heather and, in both instances, the participants seemed appreciative of the opportunities they were afforded and were motivated by a desire to help people who did not have the same support that they had.

Heather’s situation is distinct because, while her direct social mission has to do with disability issues and her educational experience as a student with ID, her indirect social mission is entrepreneurial. Heather wants to help others start businesses, whether it is as a part of her social enterprise or independently:

Heather: My dream is to have other people with Down Syndrome and other people with disabilities have clear voices to go out and speak…. I want to have all people just like me to speak and have their organization and be [advocates] for change…. I want everybody else to have a chance to speak and not just me. I want them to start their own business and they can come to me or my mother and we can help if they want to do that.

This motivation was particularly interesting (and surprisingly subversive) because it suggests an impact far beyond one social enterprise, to possibly catalyzing a social movement by entrepreneurs with disabilities.

In line with her direct mission, Julie’s indirect social mission is to help service animals. Notably, Lisa (Julie’s key support person) stated that Julie had difficulty understanding the more conceptual aspects of social entrepreneurship:

Lisa: I don’t even know if she knows what [the goal and mission] mean. I’m sure you’d get answers across the board. I don’t think she’s in a place where she cares. For her, it’s important to get out and help the service dog program, but she’s such an in the moment girl so we never made sure she knew what those things were. We’re not going out to get support so she doesn’t need the script right now. It’s never been a high enough priority to discuss that with her.

Yet, Julie articulated a vision for the larger social impact that helping her service dog program with day to day expenses could have. Not only did Julie believe that her contribution could help the service dog program provide for the animals in their care, but it could possibly enable them
to take in more animals. It could perhaps help them serve more families or serve the families that they do more affordably, recognizing the financial difficulties that families impacted by disability often experience. In effect, by helping to support the service dog program, Julie’s social entrepreneurship could help to support her community.

3. **Motivation and key support**

There were discrepancies between what the key support person perceived as motivating factors versus what the social entrepreneurs with ID said motivates them. Markedly, the key support persons tended to emphasize push factors over pull factors. For example, when Derek spoke of his motivations he mentioned he held previous jobs that he did not like. However, Charlie (Derek’s key support person) identified this as Derek’s main motivation for pursuing social entrepreneurship rather than his dream to own a business:

Charlie: He’s got disabilities and those don’t allow him to qualify for a regular job that everyday people would be able to qualify for… that being said, there are jobs out there for people with disabilities. He’s had a few or a couple jobs and it’s his social side that got in the way. He wanted to socialize a lot and nothing fit his personality. No job fit his personality so he wanted to start up his own thing.

In fact, when asked whether his previous jobs played a role in his decision to start a business Derek said, “Not really.” For Derek, the connection between his dissatisfaction with previous work experiences and his decision to start a social enterprise was tangential – Derek was motivated by the potential that new venture provides rather than by his past negative experiences. This effect, whereby key support persons emphasized push factors, was somewhat less among the two key support persons who were themselves entrepreneurs, James (Nathan’s key support person) and Mary (Heather’s key support person). However, it was still apparent.

Interestingly, the motivations identified by Lisa (Julie’s key support person) had little to do with the service dog program, which she spoke of as incidental. Rather, Lisa expressed that
the business was primarily intended as a distraction from Julie’s health problems and a vehicle for social interaction:

Lisa: For me, it keeps me going. For her, it energizes her. If the jewelry ever gets boring to her, we’ll stop doing it. If she’s thinking about something other than her health, we can focus on that and that’s good.

Interviewer: What do you think motivates her?

Lisa: For speaking, she loves telling her story and telling people about [her service dog]. She likes telling people about the service dog program and how she does things. She likes the interaction with the community and getting out there excites her. For the jewelry, it’s like a show and tell for her. She enjoys the creative side and has always been artsy. I don’t think the feedback is what she would say, but when we’re out and people ask about it, she’s very excited to tell people about it and share it with them. She’s such a social creature that if it connects her with other people, it’s really what energizes her.

Lisa’s response indicates the possibility for key support persons to conflate their own motivations with the motivation of the social entrepreneur, illustrating the dangers inherent in proxy responding. More precisely, key support persons appeared to have difficulty distinguishing between their own motivations for helping an individual to pursue social entrepreneurship and the actual motivating factors driving the individual with ID to pursue social entrepreneurship. This can be particularly problematic as it may signify a conflict of interest depending upon the support person’s role in the business and the extent to which the social entrepreneur relies upon them for carrying out their vision. The self-determination of a social entrepreneur with ID will be inadvertently limited if their key support person has a different vision for the direction of the business.

For the most part, the social missions identified by the participants with ID were not as central to the business for the key support persons. This does not mean that the key support persons were unaware of the social mission, but that the social mission did not have the same value or hold priority in the key support persons’ perceptions. The only exception was perhaps Mary, who is business partners with her daughter Heather. Like Heather, Mary is committed to
the social mission of inclusion and self-advocacy, but from the perspective of a parent-advocate so there was still some differentiation in focus. Whereas Mary had a dual focus on both the social mission of the business and Heather’s employment, for the other key support persons the central focus of the business was on employing the individual with ID. Although the discrepancies between the motivations and direct social missions identified by key support persons and social entrepreneurs with ID were clear, it was more difficult to discern the degree to which the key support persons were aware of or support the indirect social mission. Mary appears to share Heather’s vision for developing future goals around helping others’ start similar businesses. Both James (Nathan’s key support person) and Lisa (Julie’s key support person) appear aware of the indirect social missions, but that is not to say that they share the same vision in this respect. The social mission plays a significant role in distinguishing social entrepreneurship from self-employment. Discrepancies in this area can be problematic if the key support person is focused on a mission of self-employment and not necessarily that of social entrepreneurship, in which case the social entrepreneur with ID may not be getting the resources, information, or support that they need. For example, when Lisa (Julie’s key support person) stated earlier that she had not seen the need to discuss the goal or social mission of the business with Julie.

4. **Motivation and Budding Futures**

Budding futures was established on push motivations, founded by a group of parents in response to the lack of opportunities for young adults with intellectual and developmental disabilities to gain job skills, work experience, and receive at least minimum wage. The participants with ID interviewed who worked at the greenhouse (Andrew, Kimberly, and Wayne) stated their central motivating factor for working there was that their parents had
heard about Budding Futures and thought it was a good idea given the lack of opportunities to gain work experience elsewhere. Pull motivations identified by participants included not only a desire to work and for social inclusion, but also because their friends worked there and the job was fun. However, for all three of these participants, being a Team Member was not their ideal job; Budding Futures was described by all of the participants with ID working there and their key support persons as a transition job, building skills towards a next step in employment. Indeed, all three participants concurrently held other jobs more in line with their interests: Andrew is a janitor at a local college, Kimberly works at a Goodwill store, and Wayne volunteers at a grocery store and the athletics department at his local high school. Andrew, Kimberly, and Wayne are all in the transition period from the child to adult service system where they are trying to figure out what options and opportunities are available and where their parents are trying to set them up for the best possible outcome.

Andrew, Kimberly, and Wayne’s key support persons were all parents who volunteered at Budding Futures. The motivations identified by these key support persons reflected more their personal motivation than the motivation of their son or daughter. Further, the parents acknowledged a lack of pull factors in that they may not be interested in the type of work or that there were aspects of it their son or daughter did not enjoy. Push factors carried more value for the key support persons, underlying the temporary expectation of this job. For the key support persons, this job was intended to give the participant with ID work experience and something to do, amass enough work credits to qualify for disability benefits should their son or daughter need them in the future, develop skills for future employment and a strong work ethic, allow for some flexibility in scheduling, and provide a modicum of job security while they looked for other employment opportunities. In comparison, the motivations of the social entrepreneurs with ID
who had started their own businesses and their key support persons differed from participants at Budding Futures in that they were not concerned with work credits as they were already using disability benefits. The motivations of both groups of key support persons were similar, however, in recognizing a need for flexibility given competing demands for time among social entrepreneurs with ID and Team Members alike.

a. **Sharing the social mission**

A composite of participant responses provides rich information about the social mission in context and about the participants’ motivations for why they work there. According to the participants with ID, Budding Futures “was started by parents of people with disabilities and it’s a place that pays people with disabilities to come there and work” (Wayne). It is “a good opportunity to go and work, not sit around doing nothing (Kimberly) where “the goal is to train people with disabilities to give them jobs” (Andrew) and “give them a reason to believe in themselves and make their own living” (Wayne). “Their mission is to show people with disabilities that they can work just like a normal person” (Wayne).

According to the key support persons, Budding Futures is “a green house that grows plants and flower and sells them whole sale and retail” (Bill) that employs people with disabilities. It gives them “the opportunity to work” (Bill), “real job opportunities… gainful employment, a sense of purpose, and skills they wouldn’t have if they didn’t have this job” (Deborah). It gives “job training skills to people with disabilities in a safe environment where they don’t have to risk losing their job over not doing it fast enough or correctly” (Sylvia). “It’s run by people who don’t have disabilities and employs people without disabilities as well” (Deborah).
It became clear during the interviews with people with ID working at Budding Futures, that they did not share the mission of the organization. However, the key support persons interviewed were more involved. The social mission of the organization overlapped substantially with their own motivations, which is likely because Budding Futures was started by parents and therefore parents were involved in the development of the social mission from the very beginning. It could also be attributed to the key support person’s justifying the time and effort expended volunteering at Budding Futures.

While the participants with ID were grateful for the opportunity to work there, they were not a part of the organization and were motivated more by the opportunity to be paid above minimum wage for their work. This is a striking difference from the social entrepreneurs with ID interviewed, who developed the social mission and thus were integrated at the foundational level and who are in a very literal sense integral to the business itself. Making money was an important motivating factor for both groups of participants with ID, as it was seen to have implications for their quality of life. Whereas the social entrepreneurs with ID gave greater importance to their social mission, the participants with ID working at Budding Futures were more money-motivated than by the social mission. They had their sights set on futures beyond Budding Futures. Andrew is thinking about going to college and has found through working at the greenhouse that he would like to become a gardener professionally, although it is not clear if Sylvia (Andrew’s key support person) is aware of this dream yet. Over the course of their first interviews, both Kimberly and Wayne revealed that they are in the process of starting their own business partnership along with three other friends. Kimberly has always dreamed of owning a restaurant and loves working retail. Wayne would ideally like to work in a full-time, paid office position:
Wayne: Because I think of myself as a businessman… that’s why I like [the athletics department job] better. It’s more of a business. I picture myself on the telephone taking calls for the company and running errands.

Wayne sees himself as a businessperson and has a desire to be seen as a professional in this capacity. Wayne hopes the experience of starting his own business partnership will teach him “… what it takes to run a business and I won’t look at a business the same way… some think it looks easy, but it’s not easy to do.” Both Kimberly and Wayne are motivated by a desire to work with their friends, have an opportunity to make money so that they can stop working at Budding Futures, and live on their own or with friends in the near future. By starting their own business, Kimberly and Wayne may gain more control over their lives because, if successful, they will not have to depend as much upon someone else for their livelihood.

On the surface, the motivations of social entrepreneurs with ID may seem well intentioned, but unrealistic when compared to the motivations of people with ID working in a social enterprise. However, exploring the motivations of people with ID who work at a social enterprise and who also want to start their own business provides insight as to deeper factors behind the motivations of social entrepreneurs with ID beyond what people with ID engaging in other types of employment. Further insight can be provided through unpacking the structural environment within which motivations are socially constructed.

B. Structural

These interviews were conducted during a time when disability advocates in the state of Illinois were in the midst of fighting for deinstitutionalization and integrated employment legislation. In 2011 the “Ligas Decision” was entered, a class action lawsuit on behalf of individuals residing in private, state-funded Intermediate Care Facilities for Persons with Developmental Disabilities (ICF/DD). The consent decree ensures that individuals who do not want to live in these facilities will not be forced to for lack of resources and supports. If an
individual wants to live in a community-based setting, there is an implementation plan in place to provide a structure for this transition. In 2012, on the heels of the Ligas Decision, Governor Quinn introduced the “Rebalancing Initiative” and announced the closure of two state institutions, the Jacksonville Developmental Center and the Warren G. Murray Developmental Center. In 2013, Illinois passed the “Employment First Act,” which will contribute substantially towards the inclusion of people with disabilities in employment across the state. The Employment First Initiative is a national policy strategy being implemented at the state level. States that have adopted Employment First policies mandate that service providers who receive federal funding give priority to integrated employment options, affording everyone the presumption of employability, before directing consumers to center-based and day habilitation services only if necessary (Martinez, 2013; Niemiec, Lavin, & Owens, 2009). This shift in policy would make segregated and sheltered work arrangements the exception rather than the rule. The increasing number of people with ID being able to live freely in the community will increase the demand for employment services and supports in a disappointing labor market.

People with disabilities, their families, and service providers will continue to look towards social entrepreneurship as a creative solution. It bears further consideration whether, at the structural level, social entrepreneurship is going to be motivated by the lack of other available options in a market that has been saturated by discriminatory labor practices, or whether it is going to be motivated by the opportunities created in the wake of recent advancements in policy.

1. **Motivation in disability employment**

Overall, motivation has been understudied in the context of disability employment and intellectual disability in particular. The goals of economic independence and self-sufficiency are central to discussions on disability employment. This phenomenon has much to
do with how we define, value, and recognize work in our society (Lysaght, Ouellette-Kuntz, & Lin, 2012). Most people with ID and their families want to be employed, working towards the goals of economic independence and self-sufficiency (Nord, Luecking, Mank, Kiernan, & Wray, 2013). Employment confers a status of community integration and social participation that is essential for social mobility from the margins to the mainstream.

Wayne: If you make money, you have money to do things with like go out with friends, go on vacation, go out to eat... all sorts of fun things. Yes [having a job is important]. It helps pay the bills. It takes up time so I’m not always at home doing nothing. It helps keep me involved and get out there and meet people and learn what I can and can’t do and that’s about it.”

Work, however, should also be meaningful, productive, and gainful, leading to higher job satisfaction and retention. Research has found that people with ID want to work not only for pay and other economic benefits, but also because it provides an opportunity for affiliation with others, to stay busy and meaningfully occupied, for pride and satisfaction, and for new learning and experiences (Lysaght et al., 2009a). Motivation appears to play a pivotal role in determining whether people with ID gain entry to employment and retain employment for three months or more (Hensel, Kroese, & Rose, 2007). If this is indeed the case, then one would expect more research conducted in this area.

2. **Entrepreneurial motivation**

Several theoretical models have been applied in exploring the motivation of entrepreneurs. Two of the most widely used models of entrepreneurial intent are the Entrepreneurial Event model (EEM) and the Theory of Planned Behavior (TPB) model. From the perspective of TPB, entrepreneurial intent is viewed as the result of attitudes toward the behavior, subjective norms, and perceived behavioral control. Within EEM, entrepreneurial intent is the result of perceived desirability, propensity to act, and perceived feasibility (Schlaegel & Koenig, 2013). However, the applicability of these models to the disability
employment context is hindered by a lack of engagement with institutionalized oppression. Intent is only one component of entrepreneurial motivation and these models promote a normative, behavioral approach. Research has found that entrepreneurial persistence decisions are heterogeneous and vary depending upon individual values, particularly for entrepreneurs facing adversity (Holland & Shepherd, 2013).

Push-pull theory was first applied to entrepreneurial motivation in the 1980’s (Amit & Muller, 1995; Kirkwood, 2009). Whereas pull factors are typically considered to be positively motivated, push factors imply that entrepreneurship is chosen under duress, despite one’s preference and due to a lack of other options (Amit & Muller, 1995; T. Bates, 1997; Dawson & Henley, 2012; Gilad & Levine, 1986). Pull factors are widely believed to be more prevalent among entrepreneurs than push factors (Dawson & Henley, 2012; Gilad & Levine, 1986; Kirkwood, 2009). However, push factors play a stronger role during economic recession due to rates of unemployment and work-related insecurity (Dawson & Henley, 2012; Giacomin, Janssen, Guyot, & Lohest, 2011; Hughes, 2003). In 2001, the push-pull dichotomy was re-conceptualized as “opportunity-based” and “necessity-based” entrepreneurship (Dawson & Henley, 2012; Giacomin et al., 2011; Hessels, Gelderen, & Thurik, 2008; Reynolds, Camp, Bygrave, Autio, & Hay, 2001).

Push-pull motivation has been studied with regard to gender (Hughes, 2003; Kirkwood, 2009) and the social mobility of immigrants and ethnic minorities (T. Bates, 1997; Clark & Drinkwater, 2000). It has been suggested that push factors are the result of blocked opportunities and status incongruence (T. Bates, 1997; Verdaguer, 2009), and that entrepreneurship has the potential to correct this disparity to achieve status recognition (Reynolds, 2002), thereby affecting minorities differently. As regards gender differences, push factors have been
underestimated for women interested in self-employment and small business development. While they may not be the primary motivating factor, push factors do play a critical role (Hughes, 2003; Kirkwood, 2009).

Motivational factors for entrepreneurs with disabilities are often couched in the language of “benefits” of self-employment and entrepreneurship as an employment alternative (Blanck et al., 2000; Lind, 2000; McNaughton, Symons, Light, & Parsons, 2006). These stated benefits comprise seven categories: 1) participation in the mainstream economy; 2) promotion of economic growth; 3) promotion of attitudinal change; 4) improved quality of life; 5) independence, autonomy and empowerment; 6) accommodations and flexibility; and 7) integration and social participation (Parker Harris et al., in press). However, these benefits do not equate to entrepreneurial motivation *per se*. Haynie and Shepherd (2011) examined the career transition of veterans with disabilities following traumatic life events and observed a strong link between career and identity during this transformational period. During the course of their research, two types of motivations emerged: entrepreneurship as a career path based on perceived or real obstacles to other career paths (push) and entrepreneurship as a career path based on satisfying some psychological need rooted in trauma and transition (pull). This conceptualization challenges the relationship between pull-motivation and opportunity/necessity-based entrepreneurship dichotomy. Given further interpretation of these findings and in light of the current research, an argument can be made that there exists a tendency to take an overly reductionist approach to “need” in entrepreneurship literature. Within a Disability Studies context, and in particular one that values interdependence, “need” should not be designatory of deficiency or deficit. Rather, “need” encapsulates institutionalized social disadvantage – it is socially constructed. The concept of need is also relational, particularly for social entrepreneurs
who are embedded in their communities (Mair & Marti, 2006; Shaw & Carter, 2007) and for people with ID who utilize supports for self-determination (Hewitt, Agosta, Heller, Williams, & Reinke, 2013; Stancliffe, 2001). The social entrepreneurs with ID interviewed experienced a confluence of need.

Clarity in motivational factors is important to entrepreneurship policy design, which “tends to be framed around the predominance of ‘pull’ motivations” (Dawson & Henley, 2012, p. 714). Conversely, disability-entrepreneurship policy has been framed around push motivations. This raises a significant dilemma as policy developed to address pull factors and promote opportunity-based entrepreneurship will not adequately address push factors or support necessity-based entrepreneurs. In other words, social entrepreneurs with disabilities are located at an intersection where both entrepreneurship and disability employment policy come up short in meeting their needs (Caldwell et al., 2014).

C. **Reification**

There may be concern that, if allowed to set one’s own pace, one might not have sufficient work and therefore social entrepreneurship might not be an effective employment strategy. However, this is where the intersection of motivation and self-determination plays a key role. If one does not enjoy the work they are doing, they will not be motivated to do it, which will be reflected in the quality of their work and the effort they put into it:

Nathan: I can do anything I want and I get paid and it’s my dream to be an owner. I’d rather be working at this company and I don’t want to do those jobs again because it’s stressful. I don’t have to work late now or on the weekends.

It is not possible to determine from this qualitative data whether people with ID in general are more motivated to work in social entrepreneurship. However, it is clear that these social entrepreneurs with ID were more motivated to work in social entrepreneurship than the other work arrangements they had because it was a better fit. This speaks to the benefit of customized
employment. The social entrepreneurs with ID were motivated to work, enjoyed working on their businesses, and wanted to work more and to have more business.

The motivations of social entrepreneurs with ID in this research are similar to those found among nascent social entrepreneurs. Through in-depth interviews with 35 self-identified nascent social entrepreneurs attending a training program in the U.S., researchers identified five categories of motivation: personal fulfillment, helping society, nonmonetary focus, achievement orientation, and closeness to a social problem (Germak & Robinson, 2013). It is critical not to assume that these motivations are all positively-oriented. There is potential for each motivation to become counter-productive, particularly if there is no balance between monetary and social value foci (Austin et al., 2006; Germak & Robinson, 2013). In light of this finding, it is not surprising that the social entrepreneurs with ID differed from participants with ID working at Budding Futures with regards to the degree to which they were motivated by money. However, while the motivations of social entrepreneurs with ID were similar to other nascent social entrepreneurs, the socio-political environment within which they act is not. Disability was found to play a pivotal role as a motivating factor at both the individual and structural levels.

1. **Need and opportunity**

   Whereas push-pull motivation was a helpful tool in collecting data, the conceptualization of necessity and opportunity-based entrepreneurship are constructive for interpreting the findings. This raises the questions whether social entrepreneurs with ID are more motivated by opportunity than need, whether the participants with ID who worked at Budding Futures are more motivated by need than opportunity, and finally whether the key support persons are more motivated by need than opportunity. The difficulty in drawing a comparison between push-pull factors and necessity- and opportunity-based entrepreneurship is
that the latter implies that pursuing one’s interest/passion and having work that is meaningful is not a need. For social entrepreneurs, addressing the social problem or need they see in their community is the opportunity. Opportunity recognition is an essential part of the entrepreneurial process (Short, Ketchen, Shook, & Ireland, 2010) and “identification of a social need was the key criteria used to identify and recognize opportunities” (Shaw & Carter, 2007, p. 426). There exists a reciprocal relationship between need and opportunity just as there exists a relationship between push and pull factors; the one is both influenced by and influences the other.

Consider perhaps that the key support persons focused on push factors because they were thinking more in terms of necessity. This would make sense given that their role in the venture is to support the individual with ID:

Mary: We have a foundation of things set up for her, some pay, some don’t, and this is over the top of it and it’s the heart of what she does. If you work for Dominick’s, they tell you when you work and it’s more confining and this is a better set up. We wanted her to have a full, purposeful life and this works instead of a sheltered workshop or something like that and not working was not an option. The other option is to do day programming, but I’d rather her have more time than not out in the community and the programs can be her fill in. For other folks, they can’t do that or don’t have family support, but she has me and I can make this stuff happen.

However, a focus on necessity-based entrepreneurship may present a dilemma when people with ID seek support in pursuing entrepreneurial opportunities. It also bears consideration whether and to what extent opportunity-based entrepreneurship among people with ID runs the risk of being dismissed as idealistic or unrealistically optimistic. A relevant concept in entrepreneurship research is that of counterfactual thinking (Arora, Haynie, & Laurence, 2013), which complements the theory of effectuation (Sarasvathy, 2001). Counterfactual thinking occurs when one focuses on various possibilities for the future and not necessarily the facts at hand or events the entrepreneur has experienced – envisioning “what might have been” and “what yet may be.” Research suggests that counterfactual thinking and effectuation may be integral to
entrepreneurship and the process of opportunity recognition. However, within the context of ID, given the prevalence of deficiency models of disability, there is often not a presumption of credibility. Accordingly, counterfactual thinking may be interpreted as an indication of intellectual impairment rather than embraced as a possible source of innovation, creative thinking, and idea generation. To further complexify this issue, it is possible that counterfactual thinking is the result of individuals with ID having to work within a system in which people with disabilities experience institutionalized disadvantage and marginalization and wherein real change requires thinking outside the boundaries.

In some instances, close entrepreneurial ties can inspire entrepreneurship if an individual has family or friends who are entrepreneurs, as demonstrated by the interaction between Nathan and his key support person, James. There was a sense of camaraderie and mutual understanding that bonded them as entrepreneurs:

Nathan: I did it as a hobby and my friend told me to start selling it so I did, but I wouldn’t have been able to make it a business. My dad and sister don’t know how to start a business… they’re not in the business world… James knows very well because he started his own business.

While entrepreneurial ties can be positive for individuals who are taking over an existing business or starting their own, it can be a negative factor for individuals with prior experience starting a business (de Jong & Marsili, 2013). It bears consideration whether close entrepreneurial ties affect the emergence of social enterprises by people with ID. In particular, several of the participants in this research had long dreamt of being a business owner and had businesses that were previously hobbies — to what extent might close entrepreneurial ties ignite latent entrepreneurship? At what point does it move beyond being a hobby into a business and what motivating factors influence this decision?
2. **Social mission**

There is cause for concern about normativity and the social mission within a disability context. Will there be a market for businesses that do not cater to, or that undermine, institutionalized social norms such as perceptions about people with disabilities? Further, will social entrepreneurs with disabilities be pressured to conform to social norms (De Clercq & Honig, 2009) in order to be viewed as legitimate or competitive in the marketplace? This speaks to a normative influence on innovation. Recall that the EMM and TPB models of entrepreneurial intent highlight perceived desirability, attitudes towards the behavior, and subjective norms respectively. Barriers in those areas would negatively impact one’s motivation to pursue entrepreneurship. Social entrepreneurship differs from commercial entrepreneurship in that the intent hinges upon social innovation, which by definition deviates from and acts to change cultural, normative, and regulative social structures (Heiskala, 2007; Pol & Ville, 2009).

However, the institutional environment has been found to influence latent entrepreneurship, (Gohmann, 2012) and social innovation operates within this normative framework (Azmanova, 2013). Normative innovation therefore is limited in its engagement with social criticism to the extent that it produces desirable social innovation that “improves the macro-quality of life or extends life expectancy” (Pol & Ville, 2009, p. 882). There exists subversive potential for social entrepreneurs with disabilities to create change. However, in our ableist society there may not be a substantial market for it. Accordingly, subversive innovation might require creating a new market.

Concern is also raised regarding the influence of the overcoming narrative and the charity-model of disability. Disability has long been used as the justification for social enterprise development, invoking a charity-model approach rather than recognizing the agency of people
with disabilities (Parker Harris et al., 2014). Because we are familiar with this typology of social entrepreneurship, people with disabilities may be susceptible to employing a charity-model approach or having that model ascribed to their social mission and thereby misrepresenting it. For example, Derek does not have a social mission, either direct or indirect, that is related to disability. Yet, when he received media attention for his business in a recent newspaper article, it spoke only of him as a disabled business owner who overcame his disability and said nothing about his work or the quality and ethical sourcing of his coffee.

People with ID working in social enterprises, such as Budding Futures, face a different concern regarding the social mission. Typically organizations that employ and/or serve people with ID do not involve them in the business development process. For social enterprises, this means that the social mission is often created without the voices and perspectives of people with disabilities. Indeed, a study examining social enterprises serving people with disabilities in the UK found that few service users or caregivers were aware of the existence or purpose of the social enterprise (Secker, Dass, & Grove, 2003). Subsequently, even though people with disabilities and their families may be the subject of the social mission, it is not necessarily their mission or motivation for working there. That is not to say that each employee needs to be a part of business creation, as that would be impractical operationally; but, there should be representation in the process – nothing about us without us. Absent this representation, can a social enterprise working with people with disabilities ever really actualize such a social mission if the development of the mission itself is not an inclusive process?

3. **Choice and self-determination**

The social entrepreneurs with ID interviewed were motivated by a desire for self-determination: to control the direction of their own lives, to have the freedom to follow their
dreams, to do work that they enjoy, and to help people/society. Participants with ID working in a social enterprise had a different motivation for self-determination: they began working at Budding Futures because their parents thought it was a good idea, their friends also worked there, and they needed something to do. While their decision to start working at Budding Futures was not necessarily self-determined, their motivation to continue working there was. Participants saw it as a step towards the achieving the quality of life that they wanted. Kimberly and Wayne’s motivations for starting a new business in this vein were split. Wayne’s motivations were similar to those for working at Budding Futures; he wanted to start a business because his friends were doing it. For Kimberly, however, the motivations were similar to the social entrepreneurs. “Growing up I always wanted to have my own business,” Kimberly said, expressing a desire to follow her dreams and passion. It would be interesting to explore further the extent to which social mobility is motivation in employment for people with ID and the implications that the desire to create change for themselves as well as others has for social entrepreneurship.

Choice and self-determination play an essential role in the decision to pursue social entrepreneurship because it is, first and foremost, a decision. A distinction should be made between the “decision” and the “desire” to start a business. There is an element of selection bias inherent in this sample because it involves people who had the support necessary to make their choice a viable option, and their decision an actionable one. There is a connection between self-determination and having access to adequate supports and accommodations in community-based working environments, which affects the amount of choice and opportunities one feels they have (Wehmeyer & Bolding, 1999). Individuals with ID who have a desire to be social entrepreneurs may not see it as a viable choice or have the support necessary to act on their motivations. We
do not know how many latent social entrepreneurs with ID exist. Nor do we know whether their ideas are viable, marketable, or their chances of success. Regardless, it is clear that this pathway to employment may be blocked at the motivational level if the individual is not supported in making the entrepreneurial decision and does not feel as though they can effectuate that decision. Entrepreneurial self-efficacy is important not just in the decision to start a business (McGee, Peterson, Mueller, & Sequeira, 2009), but also in entrepreneurial persistence wherein an entrepreneur continues to pursue an opportunity despite opposing motivational forces (e.g., counterinfluences and other enticing opportunities). Persistence decisions vary depending upon individual values and the level of adversity experienced (Holland & Shepherd, 2013). Social entrepreneurs with ID need to be supported in making the decision whether or not to start a business and whether or not to persist over time. Both the individual with ID and their support person(s) need the information and resources to make an informed decision. The decision should be the individual with ID’s choice. The decision to start a social enterprise should be one that is self-determined and person-centered; particularly if one is to be motivated to sustain social entrepreneurship as an employment strategy in the long-term. However, motivation is only part of the picture. The next chapter will explore how participants’ motivations are being enacted, focusing on the barriers that people with ID encounter and the services and support that they utilize.
VI. MANAGEMENT: “HOW THEY ACT” 8

Business management is a complex field of study, one often inaccessible to people with ID. To counteract this, social entrepreneurs with ID may adopt creative ways of doing things – innovating in order to operate within a society wherein people with ID are marginalized and disadvantaged. In this effort, social entrepreneurs with ID encounter multiple barriers to participation and must negotiate complex and often fragmented systems of formal and informal services and support. However, until now it was unclear what those barriers were, how people with ID make use of existing services and supports in disability employment and small business development, and what additional services and supports are needed to facilitate social entrepreneurship. Understanding the management process at a very fundamental level, i.e., what they are doing as individuals and how they are doing it within the structural environment, gives valuable insight in moving forward in developing research, policy, and practice.

A. Individual

1. Management and use of supports of social entrepreneurs with ID

All of the key support people identified by participants with ID were sources of formal support, meaning that they either received payment through formal disability services to provide support as a Job Coach or Personal Assistant or they held a formal role in the business as an employee or business partner. The distinction between formal and informal sources of support in this context is not always clear, staff members or case managers may be referred to as friends or as friends of the family and in many cases they are. This is further complicated when trying to distinguish who is an employee, who is a support, and how that might change when the social entrepreneurs are at a point where they may be able to hire employees. It is telling to

8 This chapter includes information that has been published elsewhere: Parker Harris, S., Caldwell, K., & Renko, M. (in press). Entrepreneurship by Any Other Name: Self-Sufficiency versus Innovation. Journal of Social Work in Disability & Rehabilitation.
observe the limited use of the service system by the social entrepreneurs; operating outside of VR and, to an extent, attempting to control their interaction with service systems.

a. **Formal supports**

James (Nathan’s key support person) works with Nathan as his Job Coach through a program developed at his service provider for customized, independent outside work. According to James, wanting to help support Nathan’s business development was one of the reasons why the service provider staff created this program. When asked whether he thought he would have been able to start his business if it had not been for this program, Nathan responded, “No, I don’t.” Further, when asked if he would have thought about starting a business had it not been for this program he responded, “Yes, but I wouldn’t know how to go about it.”

James describes his role as “an assistant or an advisor,” but Nathan would like for James to be more of an employee one day. When interviewed, James emphasized that his role is to support Nathan with “…any independent work outside of [the service provider]. For Nathan it’s helping him start his business but for other people it might be learning how to use public transportation.” In this way James’ role is person-centered and not centered on the business itself; Nathan is primarily responsible for the business. Indeed, Nathan feels he has control over the business and is responsible for making the decisions:

Nathan: [James] helps me with the billing and how much to order… he watches that I don’t order too much. He makes sure I pay the bills and stuff. But I’m the one that makes the coffee and know the flavors.

James: When I work with Nathan I help him come up with an agenda for the day; the things that we need to do. He’s really on top of having orders and needing to fill them and getting them to people. Most of what I help him with is when we have to go to meetings or have to go to the city for licensing concerns or going on a tour of a commercial kitchen space. I help him with more administrative tasks and help him with his record keeping and help him on that side. He’s been making bags of coffee for people for four years and doesn’t need help with that. I help him build the administrative side.
James works as Nathan’s Job Coach one day a week for six hours, occasionally more if Nathan has a meeting on a different day of the week which requires support. In addition to James, Nathan has a lawyer who works *pro bono* that was recommended by his service provider from Equip for Equality, the Protection and Advocacy organization for the state of Illinois. It was through this lawyer that Nathan and James (Nathan’s key support person), learned about the possibility of opening a special needs trust so that income from the business would not jeopardize the disability benefits that Nathan receives. Nathan’s lawyer also helped Nathan apply for Self Employment Assistance (SEA) and is helping him advocate for accommodations in his application for a business license.

As mentioned previously, Derek’s uncle suggested that Charlie (Derek’s key support person) become a Personal Assistant (PA) so Derek could change his living and working arrangements. Charlie’s position as a PA *cum* employee of the business is his only source of income. There is some discrepancy between how Charlie describes his supportive role and Derek’s description, partially because it is unclear whether Charlie’s supportive role is to assist Derek or to assist the business.

Charlie: We sit down and go through everything. We go and pick up things, we get supplies, we do a farmer’s market together. Most of the physical things… wherever [Derek] can help me, he helps me. Some things just need to be sped up and I step in there. It’s not that he couldn’t do it himself, but I can just push the progress along. We check orders together, come up with emails and Facebook posts together, work on the financial side. His father and others help with that as well. Mostly everything. He’s really good about checking orders. He can do that on his own.

In actuality, Charlie assists Derek with both personal care as well as with business tasks. However, Charlie described his role in the business as “co-manager” rather than as a PA. Derek described Charlie’s role as an employee working for him. In addition to Charlie, Derek has a case manager who works for a local non-profit service coordination agency for people with developmental disabilities. Derek’s case manager oversees his trust fund.
Even though she is not a Job Coach or PA, as Heather’s business partner, Mary is a source of formal support. Heather and Mary (Heather’s key support person) share responsibilities for the business and Mary helps with scheduling, preparing presentations and materials, and managing finances. When the business began, Heather’s father created a PASS plan (Plan to Achieve Self-Support). The PASS plan helps to ensure that her eligibility for receiving disability benefits would not be compromised by income earned from the business:

Mary: All of the money goes into the business, which is the benefit of doing that. People don’t want to make too much, but with the PASS plan it all goes into business expenses and we have to be better about keeping that. We have costs with transportation and printing up forms and everything so the pass plan protects that money being eaten up.

Heather and Mary also use MAP/PATH planning to brainstorm and identify goals, and attended self-employment training at the RTC-Rural:

Mary: We went to Montana to see Ellen Griffin who works for the Rural Institute where they self employ people and it made so much sense, but it always seems to require a sidekick and isn’t done with just the individual.

Mary makes it clear that Heather’s independence within the partnership is a priority – she is an equal partner. Currently, Mary’s schedule is flexible enough that she can be there to provide Heather with support the majority of the time. However, Mary explained that if the situation changes or Heather needs additional support, personal assistance can be arranged as a business expense.

Julie has two PAs through DRS: her mother Lisa (Julie’s key support person) and a family friend, who provides personal care but does not provide support for the business. As part of her IEP, Julie has a tutor and Job Coach who works with her when she is in school on skills in public speaking and developing speeches. As mentioned previously, Lisa provides support for public speaking engagements by giving prompts where necessary. For the jewelry business Lisa’s role is more hands-on:
Julie: My role is to actually get beads and my mom cuts a piece of wire or plastic elastic stuff that I can actually do with it. I put the beads on and then my mom does both ends and the puppy charm as well. In there, I have small tools that I use... if there’s a piece of jewelry someone takes and you want that same one, I would have to make it and before I make it, I need to get their measurement.

Lisa: I’m like her background business person slash organizer… she’s like the face and PR of the business and I do a lot of the behind the scenes stuff even for the jewelry. I talk with her about what the next day will look like and she shows up and does the work and knows ahead of time about speaking engagements. I coordinate everything behind the scenes for her so she can concentrate on what she does best. For the jewelry, she’s a true designer and knows what colors and beads and look she wants. If it’s time to replenish beads, we’ll coordinate when she wants to go shopping and I’m her one on one in public.

While her parents had created a PATH plan for Julie, the formal support they utilize most is her IEP/transition plan. In order to ensure an appropriate IEP/transition plan was developed and implemented that was customized based on Julie’s strengths, her parents relied upon the formal support of a lawyer to advocate and assist in the process. Julie’s lawyer was recommended by a local CIL. Finally, Julie’s service dog is also a source of formal support, playing a fundamental role in her social entrepreneurship; their symbiotic relationship driving Julie’s commitment to the social mission.

b. **Informal supports**

While Nathan’s family had been instrumental in the gestational stage of starting his business, they are no longer involved. This was taken as a step towards independence for Nathan, primarily to legitimize his work as a business and not simply a hobby. Further, the need for independence was underscored by his family’s lack of prior experience in entrepreneurship and business. Occasionally, Nathan’s family steps in to help deliver orders, if needed, and remain an important source of social support, along with the community at Nathan’s CILA.

Conversely, Derek explained that he relies greatly on informal support from his family and friends since his business is a two person operation that consists of Derek and his key
<table>
<thead>
<tr>
<th>Table V</th>
<th>SERVICES USED IN MANAGEMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nathan</td>
</tr>
<tr>
<td><em>Job Coach/ Personal Assistant for business</em></td>
<td>Job coach through service provider</td>
</tr>
<tr>
<td><em>Lawyer</em></td>
<td>Equip for Equality</td>
</tr>
<tr>
<td><em>Accountant</em></td>
<td>Not yet</td>
</tr>
<tr>
<td><em>Living Arrangement</em></td>
<td>Independent living arrangement</td>
</tr>
<tr>
<td><em>SSI/SSDI</em></td>
<td>Yes</td>
</tr>
<tr>
<td><em>Special Needs Trust</em></td>
<td>Yes</td>
</tr>
<tr>
<td><em>Planning</em></td>
<td>Business plan for Department of Rehabilitation Services (DRS)</td>
</tr>
</tbody>
</table>
support person, Charlie. Among those working for him, Derek includes family and friends who are not working as paid employees and his case manager. Derek’s uncle, who works in commodities and stocks and had an existing relationship with Coffee Co., serves as his supplier. According to their promotional material, Derek’s uncle personally selects the coffee beans the business roasts. Derek’s father acts as lawyer for the business and occasionally as a “sort of” accountant. In addition to Derek’s father, Charlie (Derek’s key support person) explained that a friend of the family who home-schools Derek’s sister provides support to meet the accounting needs of the business. The “team” of family and friends sit down together to brainstorm ideas and decide what to do with budgeting. It is a collaborative effort. For instance, while Derek came up with the name for the business, the logo and slogan were provided by a friend of his sister. However, it is unclear what Derek’s exact role is in the management of the business. When asked whether he felt he was in control of the business, Derek replied, “Yeah. Some days I think my dad is, but for the most part I am.” His main role is in customer service and promotion, complementing one of the problems he kept running into in other jobs – his social side.

Heather and Julie’s families are similarly ingrained in their businesses. For Heather, it is in a more formal capacity, although, her father does help with finances and is involved in supporting her other employment. For Julie, her father works with her mother to provide support even though her mother is the one who is compensated as a PA. Given that Julie is a very social person, Lisa (Julie’s key support person) highlighted that the sense of community surrounding the business “energizes” Julie and gives her something to focus on besides her health. Julie and Lisa are working on building her community of peers and others as a transition step after she leaves the supportive environment of her school. Julie’s network of family and friends have contributed their experience and skill to help provide assistance with marketing materials such as
the website, logo, business cards, and acting as a sounding board. This community also serves as an important source of social support for Lisa in supporting Julie’s social entrepreneurship. Charlie (Derek’s key support person) had reported a similar need when talking about supporting Derek’s business; Charlie relies heavily upon the social and material support of their family network.

Informal supports can serve as an important source of opportunity, but perhaps an unreliable one when they are asked more as favors through informal weak ties and indirect interpersonal connections rather than organized as formal business activities. For example, Nathan hopes a family friend will agree to serve as his accountant pro bono. In addition, Nathan is relying upon the parents of a family friend to help him expand his business to restaurants in an affluent area in a neighboring state. On the other hand, without his uncle’s connections, Derek would not have had the opportunity to start a coffee business and to establish a management process to make it an actuality. Heather’s opportunity resulted from her association with professional organizations at the local and national level, which have generated contracts for work, speaking engagements outside of Illinois, and awards for leadership and self-advocacy that reinforce the legitimacy of her business.

2. **Barriers in management**

   Formal and informal networks are not only instrumental sources of support, but they are also essential to addressing barriers in providing for a particular kind of opportunity – equal opportunity. Social entrepreneurs with ID in this research reported experiencing barriers that can be categorized as: financial and economic, attitudinal, traditional-expectation, readiness and growth, systemic, and support (Table VI).
### TABLE VI

**MANAGEMENT BARRIERS FOR SOCIAL ENTREPRENEURS WITH ID**

<table>
<thead>
<tr>
<th>Barrier Category</th>
<th>Barrier Experienced</th>
<th>Need</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Financial/Economic Barrier</strong></td>
<td>• Certifications are expensive</td>
<td>• Need funding opportunities for social entrepreneurs with ID</td>
</tr>
<tr>
<td></td>
<td>• Discrimination limits funding opportunities</td>
<td>• Need affordable certification</td>
</tr>
<tr>
<td></td>
<td>• Free business development education unsatisfactory, but cannot afford paid options</td>
<td>• Need business-related financial literacy for people with ID</td>
</tr>
<tr>
<td></td>
<td>• Cannot afford to hire more employees</td>
<td>• Need to address asset limitations in policy</td>
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<td></td>
<td>• Awareness of finances, but overall lack of business-related financial literacy</td>
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<tr>
<td></td>
<td>• Concern about making too much money and losing benefits</td>
<td></td>
</tr>
<tr>
<td><strong>Attitudinal Barrier</strong></td>
<td>• Stigma associated with ID: don’t believe they can own a business or devalue ownership through charity-model approach</td>
<td>• Need to demonstrate that people with ID can be social entrepreneurs</td>
</tr>
<tr>
<td></td>
<td>• Discrimination against people with ID and exclusionary practices: leading up to entrepreneurial entry and during business development</td>
<td>• Need to better identify areas where discrimination occurs in this context</td>
</tr>
<tr>
<td><strong>Traditional-Expectations Barrier</strong>*</td>
<td>• Underestimate entrepreneurship training and support needs</td>
<td>• Need to identify training and support needs to establish best practices</td>
</tr>
<tr>
<td></td>
<td>• Social entrepreneurs’ expectations may be seen as unrealistic</td>
<td>• Need to better understand expectations of social entrepreneur, support persons, and key stakeholders</td>
</tr>
<tr>
<td></td>
<td>• Key supports’ expectations affect social entrepreneurship</td>
<td></td>
</tr>
<tr>
<td><strong>Readiness Barrier (and Growth)</strong></td>
<td>• Lack of business education, rely upon experiential knowledge</td>
<td>• Need accommodations in certification and licensing</td>
</tr>
<tr>
<td></td>
<td>• Lack of experiential knowledge</td>
<td>• Need affordable business planning and education for people with ID</td>
</tr>
<tr>
<td></td>
<td>• Lack of business planning, using other planning in lieu of a business plan (PASS, MAP/PATH, IEP/transition plan)</td>
<td>• Need to integrate and contextualize future planning methods used by people with ID</td>
</tr>
<tr>
<td></td>
<td>• Understanding of customers and market</td>
<td>• Need business mentorship</td>
</tr>
<tr>
<td></td>
<td>• Do not have business license, legal entity, or see as unnecessary</td>
<td>• Need accessible financial management</td>
</tr>
<tr>
<td></td>
<td>• Marketing relies upon word of mouth and social network</td>
<td>• Need to plan for business-related access and accommodation needs</td>
</tr>
<tr>
<td></td>
<td>• Fear of getting too big and not having adequate support</td>
<td>• Need business incubator for social entrepreneurs with ID</td>
</tr>
</tbody>
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TABLE VI (continued)

MANAGEMENT BARRIERS FOR SOCIAL ENTREPRENEURS WITH ID

<table>
<thead>
<tr>
<th>Barrier Category</th>
<th>Barrier Experienced</th>
<th>Need</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Discrimination limits growth opportunities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of planning for accommodation needs</td>
<td>Need accommodations in certification and licensing</td>
</tr>
<tr>
<td></td>
<td>Do not have access to physical space for business activities outside of home or service provider</td>
<td>Need to address policy regarding asset limitations and public benefits</td>
</tr>
<tr>
<td>Systemic Barrier</td>
<td>Difficult for people with ID to get licensing and certification</td>
<td>Need to better understand how transition affects social entrepreneurship</td>
</tr>
<tr>
<td></td>
<td>Disincentives to entrepreneurship and asset limitations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Change in support when transitioning from child to adult services affects social entrepreneurship</td>
<td></td>
</tr>
<tr>
<td>Support Barrier</td>
<td>Reliance upon service providers and schools for employment opportunities</td>
<td>Need to educate service providers and schools about social entrepreneurship for people with ID</td>
</tr>
<tr>
<td></td>
<td>Time constraints of key support person limit social entrepreneurs’ capacity</td>
<td>Need to plan for business-related support needs and allocate resources accordingly</td>
</tr>
<tr>
<td></td>
<td>Lack of support can limit start-up and growth</td>
<td>Need to better understand role of supports in start-up and growth</td>
</tr>
<tr>
<td></td>
<td>Working with family complexifies roles and priorities</td>
<td>Need to establish roles and responsibilities for family members within the business</td>
</tr>
<tr>
<td></td>
<td>Staff turnover affects formal support</td>
<td></td>
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<tr>
<td></td>
<td>Overreliance upon weak ties</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Health concerns and living arrangement may limit social entrepreneurial capacity</td>
<td></td>
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</tbody>
</table>

* Responses for traditional-expectations barriers were primarily given by key support persons.
Both Nathan and Derek ran into barriers regarding licensing and certification. It is a difficult and costly process to become certified as a fair trade or organic vendor, particularly for someone who has ID and for whom the certification process is not available in an accessible, plain language format. Nathan and Derek both worked around this by utilizing suppliers that had already obtained these certifications. Because they are both selling a perishable food/beverage product, the city requires that Nathan’s and Derek’s businesses obtain sanitation certification, following the successful completion of a food service sanitation course. This course is also not offered in an accessible format. Nathan addressed this barrier by having his key support person, James, take the exam. However, this is only a temporary solution as his business now relies upon his Job Coach for its sanitation licensing. Utilizing a shared kitchen space will hopefully be a step towards a more permanent solution for Nathan. For Derek, he and Charlie (Derek’s key support person) took the sanitation licensing course together. Charlie was able to facilitate so that they both obtained the necessary certification. Similarly, when Nathan applied for SEA funding, he and James were initially told that Nathan could not have assistance in filling out the forms. Thankfully, Nathan’s lawyer from Equip for Equality was able to facilitate in making sure the necessary accommodations were provided. Currently, Nathan is trying to get his business license. He is the only social entrepreneur that was interviewed who is planning on doing so.

The main financial and economic barriers identified by participants comprised a lack of financial literacy among the social entrepreneurs with ID, and the key support persons did not appear to be making much effort to involve the social entrepreneurs in financial management. Conversely, the parents of participants with ID working at Budding Futures all had different strategies to build skills around money and account management. The social entrepreneurs with
ID were most aware of the threat of losing their benefits should they make “too much” money (Heather), which is a disincentive to growth of their business.

At first glance, the attitudinal barriers relayed by social entrepreneurs with ID related to their motivation for starting a social enterprise. For example, Heather’s desire to show that people with ID can be self-advocates and be included in education. However, deeper analysis of Nathan’s response indicates a relationship with the desire to be seen as a business owner and the perception regarding the viability of business ownership for people with ID.

Nathan: That one teacher in high school really ruined me. She said I couldn’t do anything and don’t dream dreams. At that time it really got to me and I didn’t know how to express my feelings so I kept it to myself and I got really, really depressed so much that I had to be in the hospital…. If people tell you because of your disability that you can’t dream dreams, I tell them it’s not true. You just try and try again and if it doesn’t work, then it’s not for you and you try something else.

Recall that Nathan’s indirect social mission is to show that people with disabilities, including ID, can be business owners; a motivation driven by his previous experience in a special education classroom. Within the context of social entrepreneurship, attitudinal barriers appear to be closely related to the stigma associated with ID in business.

The majority of the barriers identified by participants can be categorized as barriers to readiness with regards to starting a business, business development, and growth of the enterprise. One of the key components to starting a successful business is business planning. Creating a business plan and conducting a feasibility assessment have become integral components of the self-employment literature for people with ID. However, this was lacking among the social entrepreneurs interviewed here, some of whom created ad hoc business plans and others using disability-specific planning tools in lieu of business planning. Derek and his family created an initial business plan, but it soon fell into disuse. Nathan and his key support also created a business plan, since it was required when they applied for SEA funding and assistance from
DRS. However, it is unclear whether their plan was implemented or involved an implementation strategy. Heather and her mother, Mary (Heather’s key support person), intentionally decided not to create a business plan. Mary had done so previously for other businesses, and felt it was not necessary for Heather’s business. Instead, Heather and Mary used a PASS plan to manage the financials and MAP/PATH planning to brainstorm and stay goal-oriented. Julie and her key support also did not make a business plan, but rather Lisa (Julie’s key support person) has been using a combination of PATH planning and primarily Julie’s IEP/transition plan. Worth noting, the goals of both of these planning processes are non-monetary and have less to do with business aspects than they do with future planning and skill development (Table VI). While the creative use of disability-specific planning tools can supplement and serve as an adaptive method for business planning, these tools should not be used as a substitute for developing a business plan.

Other barriers to readiness and growth include having a marketing strategy limited to word of mouth and a lack of knowledge about one’s customer-base and the market. When asked whether they received any training or education in business or whether they felt doing so would be helpful, the responses of social entrepreneurs with ID and their key support persons appeared to value experiential knowledge over business education. At the same time, they acknowledged having a lack of experiential knowledge. Nathan and James (Nathan’s key support person) tried to gain information by attending a session at a Small Business Development Center (SBDC), but found that “it was basically a commercial for the paid course” (James) and are looking into other sources of information. In creating their business plan, Nathan and James relied upon the resources available to them at the public library and on the internet. Notably, Heather spoke about the importance of getting a general education to starting a business:

Heather: I advocate for people to get education before they start a business so they know their purpose for the business. My advice to people is to get education, learn about what
a business means, what it takes to have a business and a purpose in life, and what your business is going to be called. You need to learn professional versus personal. You need to know exactly what a professional means and look good and dress nice and when you talk about what you want to your audience.

In social entrepreneurship literature, there has yet to be discussion about the role of special education or the impact mainstreaming may have. Barriers to readiness for social entrepreneurs with ID involve not only access to business education, training, and information, but at the most fundamental level equal access to education.

For Derek and Nathan, the barriers to readiness as it pertains to growth of the social enterprise include not being able to afford to hire employees despite wanting to:

**Interviewer:** What were the main problems or obstacles you faced in starting this business?

Derek: I started it just slowly. No, but there are people who have said they want to their kid or young adult working and just need a business. I wish I could have the authority to hire.

Both Nathan and Derek responded that they did not necessarily need to hire at this point, but wanted to hire in the future as their business grows. For Nathan, he is waiting on getting his business license before doing any growth activities:

Nathan: Right now it’s just friends and word of mouth…. Once I get a business license I think people will get it, but I don’t want to send it away until I get that. For now, it’s just… friends because I don’t want to get in trouble for not having a business license.

Growth is an essential component of social entrepreneurship, and the desire for growth served as inclusion criteria for participation in this research. However, several key support persons were concerned about growing too much or too quickly, exceeding the social entrepreneurs’ capacity for supply to meet demand. Lisa (Julie’s key support person) shares this concern with regards to her daughter’s business. Because of Julie’s health concerns, Lisa does not want to do too much promotion outside of their community network:
Lisa: It’s hard knowing there’s so much more we could do to market it, but that could be bad too because she only has so much energy to speak and make jewelry. We don’t want to over-publicize if she won’t be able to do it.

This reveals a tension between the social entrepreneurs’ desire for growth and the support person’s need not to exceed capacity. Accordingly, support persons may be actively constraining demand for a product/service to control the rate of growth. On the one hand, the support person may be approaching the issue from the perspective of knowing how much support they can provide or being protective of the individual with ID. On the other hand, this kind of support raises concern around issues of paternalism, self-determination, and the extent to which the social entrepreneur with ID is involved in such decisions affecting their business.

Like Lisa (Julie’s key support person), Nathan indicated a relationship between growth and the amount of support he received from his Job Coach. Currently, James (Nathan’s key support person) works with him one day a week and that determines when he can spend time on business-related activities for which he needs support. Thus, Nathan must schedule his business activities around his Job Coach’s availability and the number of hours of support he receives from the state, rather than around his support needs for the social enterprise. Derek also experiences barriers in support due to time constraints of his key support person:

Derek: He really likes this job, but some days he can’t make it on time and I just wait because I know he’ll show up, but sometimes he doesn’t come those days…. Just some of the days where Charlie doesn’t come in – those are the hardest days because then those days I have to just count the bags and count the purchase orders so that just takes time.

Because Charlie is both Derek’s PA as well as his cousin, there is confusion around his role in the business and his responsibilities as an employee. Recall that Charlie described his title as co-manager whereas Derek described him as his PA. Their relationship as family members appears to be a mitigating factor that tempers Derek’s enforcement of his managerial position and enables Charlie’s laxity.
3. **Management and Budding Futures**

The management structure at Budding Futures is traditional in that its social mission is to employ people with intellectual and developmental disabilities, and only people without disabilities are employed in management positions. Budding Futures is not traditional in how people with ID and their key support persons are involved in the organization. In this context, advancement does not refer to a pay raise or a job promotion. Rather, in a broader sense, advancement refers to payment which meets the minimum wage, at least, and opportunities for more integrated and competitive employment elsewhere in the future.

The key support persons interviewed noted that some parents view the membership fee for Budding Futures as a burden or disincentive. However, the key support persons argue that this as an investment of time and money that provides an opportunity for people with ID to gain valuable work experience and develop job skills. Although, perhaps more importantly for the key support persons, the membership fee serves as an investment that ensures an individual with ID will have the opportunity to get the job credits they need to qualify for disability benefits.

Budding Futures allows Team Members to set their own hours, thereby providing a flexible and secure work arrangement. Scheduling hours to work is the Team Member and support person’s responsibility if they want to be paid and to earn the work credits they need or, to put it in business terms, if they want to see a return on their investment.

Budding Futures does not offer Team Members the opportunity to gain leadership or management experience. Participants with ID reported that they do not have a decision-making role and did not feel they could give ideas or suggestions to the staff. Indeed, when asked they appeared not to have thought about contributing ideas or suggestions to improve aspects of the business or address aspects they did not like. This is perhaps the biggest difference between the
participants with ID working at a social enterprise versus the social entrepreneurs with ID.

Social entrepreneurs with ID express feeling more self-determination and control in their work; they get to choose the work they do and it is customized to their unique interests.

The management structure of Budding Futures raises questions regarding the possible artificiality of the work environment if, as Bill (Wayne’s key support person) stated, “A special needs worker is being subsidized by a parent.” There exists a strong element of paternalism involved when considering that the parents are indirectly funding their paycheck. Further, this holds significant ramifications regarding the commodification of work. What does it mean if the labor (or “work experience”) of people with ID is a commodity that can be purchased? What does it mean that parents feel they have to make this “investment” in order to secure their child’s future in response to government restrictions? Moreover, does it matter if this is only a temporary work arrangement and if the Team Members seem happy, enjoy the work, and appreciate the opportunity to earn work credits in a flexible and safe environment? Research has shown that students who have work experience on their resume during secondary education are more likely to have employment as a post-school expectation, particularly if it is paid employment, in an “authentic workplace”, and if vocational supports are in place (Nord et al., 2013). Of course, it matters. Understanding the structural environment will give further insight into the reasons why.

B. **Structural**

In June of 2012, the Government Accountability Office (GAO, 2012a) examined the extent to which federal programs were supporting employment for people with disabilities. The GAO’s report found a fragmented employment service system which overlapped among various government agencies, particularly with regards to programs for veterans and youth (Table VII).
The GAO report also highlighted that while most programs tracked at least one outcome, typically entry into employment and retention, these outcomes said little about the effectiveness of the programs overall. The report’s findings become even further emphasized when looking at those programs offering entrepreneurship training and support.

### TABLE VII

PROGRAMS OFFERING ENTREPRENEURSHIP TRAINING AND SUPPORT

<table>
<thead>
<tr>
<th>Program Category</th>
<th>&gt;50%</th>
<th>&lt;50%</th>
<th>Extent Unknown</th>
<th>Subtotal</th>
<th>% of Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service members, veterans, and/or their families</td>
<td>2</td>
<td>1</td>
<td>6</td>
<td>9</td>
<td>20%</td>
</tr>
<tr>
<td>Students, transition age youth, and/or young adults</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Serve all people with disabilities</td>
<td>-</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>9%</td>
</tr>
<tr>
<td>Programs that limit eligibility to other populations</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>7</td>
<td>16%</td>
</tr>
<tr>
<td>Subtotal</td>
<td>3</td>
<td>6</td>
<td>13</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>% of Total (N=45)</td>
<td>7%</td>
<td>13%</td>
<td>29%</td>
<td>49%</td>
<td></td>
</tr>
</tbody>
</table>

1. Service provided to more than 50% of program participants.  
2. Service provided to less than 50% of program participants.  
3. Service provided, but extent unknown.*

Of these government programs, 49% (n=22) offer entrepreneurial training and support. In the majority of categories where programs offer entrepreneurship services, these were reported as being provided but the extent to which they were provided was unknown.

Of the 22 programs that offer entrepreneurial training and support, only three (14%) reported providing the service to more than 50% of program participants; six programs (27%)
reported providing the service to less than 50% of program participants; and 13 (59%) reported
that the service was provided, but the extent unknown. This indicates that such programs may
have no effective way of measuring how many entrepreneurs they are serving or the
entrepreneurial outcomes.

Just two months later, in August of 2012, the GAO released a report on entrepreneurial
assistance programs. This report also illustrated a fragmented system of support for
entrepreneurs; one that does not interact with the previous report. In fact, the only place where
disability is mentioned is under the description for individuals served by SBDC’s (GAO, 2012b).
This division between entrepreneurship programs and disability employment programs is
pervasive. In 2003, the Department of Labor initiated a project called Growing America through
Entrepreneurship (Project GATE) in collaboration with the Small Business Administration
(SBA). This project was intended to serve people on unemployment insurance (UI) and
disability benefits through demonstration sites chosen in SBDC’s and general entrepreneurship
programs. However, while the demonstration sites serve some people with disabilities, SBDCs
and entrepreneurship programs may not necessarily make an effort to outreach to people with
disabilities and collaborate with CILs and state VR offices. Not including disability as an
important characteristic in entrepreneurship and small business development programs is
problematic because it maintains hegemonic policy silos that segregate entrepreneurship and
disability employment; thus implying that entrepreneurs with disabilities have to choose one or
the other – prioritizing self-sufficiency or innovation (Parker Harris et al., in press).

In addition to addressing the problems identified in the GAO report, what is needed to
address gaps in policy is research that examines other systems affecting entrepreneurship,
above VR. This includes passive barriers such as lending practices in the financial sector, the
lack of concerted outreach by SBDC’s to people with disabilities, and the omission of disability from inclusion in Minority and Women Owned Business Enterprise (MWBE) programs. However, there is also a great need to examine systems that are imposing active barriers for people with disabilities such as earned income restrictions and asset development limitations, as well as disincentives such as the threat of losing personal assistance services or health insurance. These gaps have been identified and supported by the literature for over a decade (Parker Harris et al., in press).

For example, work incentives for starting a business offered by the SSA include: PASS plans; income thresholds for Medicaid; property essential for self-support; impairment-related work expenses (IRWE); blind work expenses; and self-employment subsidies (Oates, 2010). However, an incentive-based policy approach does little to facilitate building assets and the limitations imposed by public benefit programs actually discourage saving (K. Harris & Weinberger-Divack, 2010; National Council on Disability, 2005).

A recent audit report by the SSA found that people with disabilities were “hiding self-employment income” (OIG, 2013), although the SSA’s methodology contained a good deal of selection bias, drawing its “random” sample from a pool of participants that met criteria indicative of overpayment. In addition, of the fifty individuals selected by the SSA who met these criteria, only five were found to be concealing self-employment income by reporting it under their spouse’s name. The exaggeration of these findings acts to stigmatize people with disabilities who are attempting to become more financially self-sufficient; further disadvantaging a population that is already systemically disadvantaged – the reason they are seeking social insurance in the first place.
Several promising asset development initiatives have emerged, which entrepreneurs with disabilities may not be aware exist (Parker Harris et al., 2013). For instance, an Individual Development Account (IDA) is a matched-savings program, authorized through the Assets for Independence Act of 1998. IDAs enable low-income entrepreneurs to open a savings account that is exempt from public benefit asset tests. Some people with disabilities, particularly those with intellectual and developmental disabilities, have been using supplemental-needs trusts, often referred to as a special-needs trust:

Nathan: If I make a lot of money, the thing I have to be careful about is losing my benefits. I could put it into a trust fund and I have a lawyer now that helps people with disabilities who try to get businesses.

This trust operates under the provision of a parent or guardian and allows individuals with disabilities, as the beneficiary, to accrue assets that are not countable in public benefit qualification. The problem with this strategy is that it requires individuals with disabilities to relinquish control of those accounts to a guardian. Reintroduced to Congress in 2013, the Achieving a Better Life Experience (ABLE) Act would address this concern by allowing people with disabilities to maintain control over their funds and also to contribute funds to ABLE accounts, thereby promoting financial independence and consumer control (K. Harris & Weinberger-Divack, 2010). Several additional strategies for addressing SSA disincentives to employment have been recommended by the National Council on Disability (2005) including easing the cash cliff for beneficiaries, reducing restrictions on assets, decreasing the complexity of program rules governing income and resources, and improving coordination and collaboration among multiple public and private systems.

1. **Support in disability employment**

There has been an increasing demand for public-funded services and supports for people with I/DD living at home with their families, due in part to the fact that people with ID
are living longer, but also due to a shift in funding. Whereas Medicaid previously focused on supporting individuals living in residential facilities, it now focuses on providing home and community-based support through waiver programs. This shift raises the question of how best to meet the needs of consumers and provide support in this context (Hewitt et al., 2013).

Work experience, be it paid or unpaid, has been identified as a best practice for individuals seeking positive employment outcomes (Landmark, Song Ju, & Dalun Zhang, 2010). However, in seeking transition and adult services in employment people with ID and their families must navigate multiple service systems (e.g., schools, state VR, state or regional developmental disabilities agencies, workforce investment systems) with collaboration among these services influencing outcomes in employment (Nord et al., 2013). A growing number of people are being placed on waiting lists for services, such as the Prioritization of Urgency of Need for Services (PUNS) in Illinois. This has led to an “overreliance” on Medicaid as a primary source of funding (Hewitt et al., 2013). Given the complexity of the situation, it is no wonder that people with ID and their families are seeking creative solutions to obtain needed employment services. This also elucidates the motivations for pursuing work at social enterprises such as Budding Futures or in starting one’s own social enterprise. As Wayne explained, “I’d probably keep [the new business] more than [Budding Futures]. I think [Budding Futures] is just keeping me on my feet until I get paid at [my volunteer job] or other places. Once I work other places, then I’ll have job credits coming in from somewhere else and I can drop [Budding Futures].”

Since the 1980’s, supported employment has been promoted as not only an effective employment strategy, but a cost-effective one from an economic and employer standpoint (Cimera, 2008, 2011, 2012; Nord et al., 2013). There has been little growth in supported
employment since the mid-nineties (D. M. Mank & Grossi, 2013), and slight developments in the area of supported self-employment (Hagner & Davies, 2002; Rizzo, 2002) have since been superseded by advancements in customized employment (Griffin, Hammis, Geary, & Sullivan, 2008). However, there are currently no established evidence-based best practices for self-employment as a customized employment strategy and for providing support to individuals with ID pursuing self-employment. As a result, there is little guidance for people with ID, service providers, and support persons in how to pursue social entrepreneurship: how to act/actualize social entrepreneurship, how to navigate a fragmented system of services, what the process involves or may look like, what barriers social entrepreneurs encounter, and what services and supports facilitate social entrepreneurship.

2. **Support in entrepreneurship**

Resources and social networks are essential to entrepreneurship. Whereas resources may be financial, human, or informational, social networks serve as a vehicle for acquiring the resources needed to recognize opportunities or to be competitive (Alvarez & Busenitz, 2001; R. A. Baron, 2007; Zeyen et al., 2012). For example, recall that Heather receives most of her business through word of mouth marketing among her social network, “My cousin knows someone who has Down Syndrome and can give them information because that’s when they hear about the business.” Additionally, Julie’s business began generating interest through a community-based website, “She started making a few things and talking about it on her [website page] so friends and family could keep in touch and it went from there” (Lisa, Julie’s key support person). Social networks have been described as the “number and quality of social ties to others” (R. A. Baron, 2007, p. 173). Meanwhile, social capital has been described as both a glue holding networks together and as a lubricant, helping networks to function better
Much like how Derek’s uncle was able to leverage his business relationships to strengthen Derek’s social capital, making the coffee business possible, or how Nathan hopes to leverage his friendships to gain access to customers in a potentially lucrative market.

Regardless of criticism at a theoretical level (Abbott, 2009; Adkins, 2005; Light & Dana, 2013), social capital is a concept that has been gaining interest within the intellectual disability community (P. Bates & Davis, 2004; Condeluci et al., 2008; A. C. Hall & Kramer, 2009; Potts, 2005). This is largely due to research that has found people with ID to have significantly smaller social networks than the general population and the implications that has for social integration (Bigby, 2008; Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson, Emerson, Gregory et al., 2001) and employment opportunities (Eisenman, 2007; Forrester-Jones et al., 2004). It has been suggested that employment is an opportunity to build social capital and strengthen social ties. While the workplace may provide greater opportunities for social interaction, these interactions may not be reciprocal or provide social support (Jahoda et al., 2008). This finding corresponds with entrepreneurship literature in recognizing that social capital is not an outcome, but rather it is a process involving both structural and relational aspects (Anderson & Jack, 2002).

Interestingly, entrepreneurship strategies are being applied to supportive arrangements for people with disabilities, outside of employment. For example, the Illinois Association of Microboards and Cooperatives (IAMC) is a grassroots effort driven by principals of self-determination. IAMC provides services and training to organize PATH planning, which identifies goals and action steps towards achieving those goals; microboards, which are non-profit organizations designed to serve one individual who serves as the core member of a Board
of Directors consisting of support persons; and human service cooperatives wherein a group of support persons come together to register with the state as a certified service provider to serve one or more persons. In light of recent discourse around corporate personhood and whether corporations are people, such innovations in the provision of disability support may be introducing the question of whether people are corporations. More importantly, it bears consideration whether and to what extent our system of services and supports are creating a culture of neoliberal commodification wherein people with ID and their families are compelled to provide subsidization.

C. **Reification**

For the social entrepreneurs with ID in this research, the management process involves mobilizing resources by negotiating between formal and informal support networks. Strengthening one’s network is seen as a means for social entrepreneurs to circumvent barriers they experience in comparison with commercial entrepreneurs. Accordingly, it is suggested that successful social entrepreneurs will develop a rich network of resources and contacts as well as the skills to effectively leverage and manage network relationships (Austin et al., 2006).

Building and nurturing network relationships was the part of the management process that the social entrepreneurs with ID excelled at. The key support persons all remarked upon the social entrepreneurs’ skill and talent in interacting and connecting with customers. The social entrepreneurs with ID expressed enjoyment and pride in customer service as well as in cultivating business relationships. In comparison, the participants with ID working at Budding Futures enjoyed the social interaction that their work provided, but reported a lack of opportunity to interact with customers and a desire to be more involved in customer service. However, the organizational structure of Budding Futures limits involvement and does not provide a channel
for Team Members to provide feedback, as will be discussed in greater depth in the subsequent chapter. This has the result of limiting self-determination, which prompted Kimberly and Wayne to start a business of their own where they would have greater choice and involvement in their work.

1. **Barriers and accommodations in management**

Social entrepreneurs with disabilities (other than ID) encounter barriers to start-up and growth in three areas: 1) education, training, and information; 2) finance, funding, and asset development; and 3) networking and supports (Parker Harris et al., 2013). The barriers experienced by social entrepreneurs with ID were similar to those in the area of education, training, and information in that there is a need for better access to information in general, but especially in understanding how policy and disability benefits relate to social entrepreneurship. Where social entrepreneurs with ID differ is that this information needs to be provided in an accessible format. Additionally, there is an educational disparity between the participants in this research and those in the larger research project (PTI). Many of the social entrepreneurs with disabilities in general received post-secondary and graduate level education and had the opportunity to receive business education even if they did not choose to pursue it (Parker Harris et al., 2013). Now that more people with ID are engaging in post-secondary education, it will be interesting to learn whether and to what extent they have access to a business education.

Participants with ID differed substantially from social entrepreneurs with disabilities in general regarding barriers in finance, funding, and asset development. While both populations experience asset poverty and a fear of losing benefits, most of the participants with ID interviewed were not in control of their finances and were not in a position to apply for lending from banks and financial institutions. Further, when applying for funding the process is not
accessible for people with ID who require accommodations such as material written in plain
language and appropriate supports.

The experiences of social entrepreneurs with ID in networking and supports were similar
to social entrepreneurs with disabilities in general; both rely upon a combination of formal and
informal support networks. However, social entrepreneurs with ID appear to rely upon both
more, with family more involved and often playing an essential role. There is a perceptible
degree of embeddedness, which speaks to the relationality and interdependent nature of social
entrepreneurship for people with ID.

Throughout the interviews, the social entrepreneurs with ID downplayed the barriers they
experienced. This did not appear intentional, but more so that they were focusing on trying to be
successful in their business. For instance, when asked explicitly about whether she had
countered any barriers or difficulties in starting and running her business, Heather said:

Heather: No, there’s no problems based on anything. The group of students that I teach,
they were most respectful and the schools were too... No, no negative. Everyone was
very positive. There’s no problems with the business. We plan out what we do in life and
we do have a plan based on dreams and we do that because it’s helpful to be positive and
not negative.

An explicit discussion of barriers had manifested instead as counterfactual thinking. Probing
questions that asked social entrepreneurs with ID about their personal experiences were more
successful in elucidating the actual barriers they had encountered. In entrepreneurship research,
it has been suggested that negative counterfactual thinking can have a negative effect on
entrepreneurial self-efficacy (Arora et al., 2013). This finding may help explain why the social
entrepreneurs with ID interviewed were more positive, wanting to maintain their sense of
entrepreneurial self-efficacy. Further, it is possible that social entrepreneurs with ID may
actively choose to downplay barriers in order to avoid people thinking they cannot be business
owners, choosing instead to portray a strengths-based image rather than reinforce a stigmatized
one. For example, some of the participants spoke about things that could be barriers, but that they did not feel were barriers for them, priding themselves having overcome these perceived barriers.

The most significant, but least talked about barrier observed in conversations with social entrepreneurs and their key support persons was that of expectations. In particular, the key support person’s expectations have massive potential to influence the direction of one’s social entrepreneurship, from ideation to entrepreneurial decision through start-up development and growth. A support person’s lack of knowledge or experience can be a barrier in two areas: business/social entrepreneurship and disability/intellectual disability. These barriers limit their ability to provide support and accommodations that will allow the social entrepreneur to work effectively. The social entrepreneurs interviewed here all had the support necessary to start their businesses. However, it remains to be seen whether they have the support necessary to grow and to persist should that support lessen or their support needs change. The support needed to start a business differs from that needed to grow one (Mueller, Volery, & von Siemens, 2012) and key support persons for social entrepreneurs with ID need better information and resources in order to provide adequate support.

2. **Services and supports in management**

There is an overlap between formal and informal sources of support in social entrepreneurship where personal and professional interact. Working with family is complex: on the one hand they know the social entrepreneur well, are often willing to work affordably, and should know how to support them best, but on the other it can be difficult to separate personal issues from business issues. This is particularly true when roles and responsibilities within the business are not well defined. For example, Charlie (Derek’s key support person) remarked that
everyone is trying to do everything and it can become difficult prioritizing, “People put the business over the personal side, we do, and it’s hard to prioritize that… so it’s hard to say you need to do this for yourself first… We want to make money, but it’s stressful to say how much you want to invest in the business.”

There is concern that the key support could define their role using a deficiency model of disability. To explain further, that the key support person perceives the barriers identified as tied to a functional aspect of disability (either physical or intellectual), which impedes the individual with ID’s ability. Further, that the role the key support person assumes involves taking over an aspect of the business because the key support person’s functioning is not perceived to be impaired in that way. While the intention may be to help, this is actually a paternalistic approach to support provision that undermines agency and self-determination. A more constructive approach would be to facilitate the social entrepreneur in these areas. From a social learning perspective, supports emerge as a valuable source of information and role modeling. For example, Heather learned a lot about how a business is run from her father and Nathan learned a lot from James’ (Nathan’s key support person) own experience with entrepreneurship. But, support is not one-directional; it goes both ways. The social entrepreneur helps others who are in “support” roles. For example, Derek is the main source of employment for his cousin and Heather's social mission is tied to helping peers learn to become self-advocates. The disjunction between the language of supports and interdependence is amplified accordingly.

Service providers are in a position to help social entrepreneurs with ID considerably by connecting them with other services they need both for the business (e.g., legal services, job coaching, etc.) as well as with other areas of independent living that, while they may not provide direct business support, support the social entrepreneur. Even when not connected through a
service provider or community organization, networking with other disability organizations can be a useful business tool for marketing, getting contracts for work, promotion, and growing one’s customer base.

People with ID receive conflicting information: get off of benefits and become self-sufficient, but only if you are not using public benefits. For all of the participants in this research, public benefits were a necessary part of their livelihood now and in the future. The participants working at Budding Futures were working to accumulate enough work credits to qualify for Medicare if, in the future, they were unable to secure employment which paid a living wage. Self-sufficiency was a goal for everyone participating in this research in one way or another. However, as will be discussed in more depth in the next chapter, the meaning of what it means to be “self-sufficient” changes. Success in social entrepreneurship is not contingent upon an absence service use.
VII. OUTCOMES: “WHAT HAPPENS WHEN THEY ACT”  

The meaning of “outcomes” in disability employment differs substantially from its meaning in social entrepreneurship. Disability employment focuses on financial self-sufficiency and independence whereas social entrepreneurship focuses on profit, innovation, and growth. It therefore becomes essential to understand what the meanings of these concepts are for people with ID participating in social entrepreneurship in order to interpret the outcomes that result. Often a quantitative approach is taken to assessing and evaluating outcomes in disability employment. However, research in the area of disability-entrepreneurship is underdeveloped, leading to a lack of appropriate and effective outcome measures/variables. The use of a qualitative approach to understanding outcomes allows for exploratory findings that come directly from individuals with ID actively participating in social entrepreneurship. This information can be used to inform the development of outcome measures moving forward to challenge how outcomes are traditionally assessed in disability employment and entrepreneurship policy at the individual and structural level.

A. Individual

1. Outcomes for social entrepreneurs with ID

In discussions with social entrepreneurs with ID, outcomes were spoken of broadly and were not defined a priori. Rather, space was provided in the conversation for participants to contribute suggestions generated from their experience of what happens when they act. Surprisingly, the outcomes revealed paralleled the inclusion criteria for participation in the research and were closely related to the mission of the business, both direct and indirect.

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9 This chapter includes information that has been published elsewhere: Parker Harris, S., Caldwell, K., & Renko, M. (in press). Entrepreneurship by Any Other Name: Self-Sufficiency versus Innovation. Journal of Social Work in Disability & Rehabilitation.
a. **Profit and self-sufficiency**

The social entrepreneurs with ID participating in this research wanted to make a profit, and articulated reasons explaining why. However, a desire for their business to make a profit did not necessarily coincide with a desire to achieve self-sufficiency. For instance, when Nathan was asked what he wants to see for the future of his business, his response was, “To make a profit and to take some of the money out of the business for myself.” He explained that he did not expect profit to be an immediate outcome, but rather viewed it as something he hopes to see further “down the road” as indicative of his success. For Nathan, making a profit meant having enough money to continue running the business and eventually having enough money to pay for things that he currently could not afford both for the business and for himself. However, Nathan was clear that he does not want to become self-sufficient:

Nathan: No. I would feel more comfortable having state funds because if the business goes down, I don’t want to support myself completely. It’s easier for me now so I don’t have to worry.

A sense of security is conveyed by reliance upon public benefits, one which should not be taken at face value. Nathan’s statement belies a much deeper problem of financial insecurity. If it were not for mechanisms of formal support systems, he would not have been able to start his business. Yet, his business is not yet self-sustaining and until that point (and perhaps beyond) his livelihood will continue to rely upon public benefits.

For Derek, making a profit would mean being able to do with the business what he wants and to improve aspects of his life, such as someday living on his own or with a friend and learning more about coffee. With regards to the former, it seemed as if Derek is waiting for the business to be more successful before becoming more involved:
Interviewer: Is there anything you would like to change about the business?

Derek: I don’t like to have that power… Somewhere in between the light and the dark is a medium. And then there is espresso and Turkish!

With a bit of levity, Derek explained that he does not really wanted to have complete control, as he enjoys working with others and his family in particular. Even though Derek is the figurehead, his business is relational and he makes decisions with his family and other support persons acting as advisors. That said, Derek has a lot of ideas that he is waiting on pursuing, some of which may be considered less practical or immediate, but which may actually be business activities essential to growth. Meanwhile, Derek’s family “team” is focused on meeting the practical, day-to-day needs first and foremost. In other words, once the business makes more of a profit, Derek will have greater entrepreneurial freedom.

When Heather was asked whether she hopes to make a profit she responded, “Yes, that’s the goal, we need to get more money. Mainly it will help to go to school.” For Heather, as with the other social entrepreneurs with ID, profit is connected to plans for the future and spoken of as a vehicle for self-determination. Julie would like to travel, particularly to India where she could learn more about the jewelry made there. For Julie, however, the central reason for making a profit was so that she could continue working towards achieving her social mission. Overall, profit appeared to have less to do with money than it did with access to opportunities to improve one’s quality of life, to improve the quality of products or services, and to help others.

b. Growth

The social entrepreneurs with ID spoke about ways they wanted to grow their businesses. When asked about where they would like to be in one year and in five years, their responses for the immediate future were more practical than their dreams for the more distant future. Nathan wants to “start small and get my name out in Chicago first” before
expanding into a market in a nearby state. For now he is happy working with James (Nathan’s key support person) and is looking forward to working in the shared kitchen. However, Nathan would ultimately like to see the business grow “really big” to the point where he can open up a store front and hire employees (with and without disabilities) to help with sales and distribution:

Nathan: If not 5 years, then 10 years, I want to have my own building. Like a big place where I can roast the coffee and after that get myself established… open up a coffee shop and hire employees. Then I can be head boss and come in once in a while to make sure they’re doing their jobs and I’d give them good money and good benefits. I would not give the top people like managers a raise first, I would first give the employees raises. I think its right to do that because I feel my company is for equality and fair trade.

It is fascinating how Nathan’s social mission extends to his desire for fair labor practices, speaking to the relationship between his experience in employment and his interest in fair trade. Derek would also like to expand to a storefront:

Derek: Yeah, I’m getting ready and it might take time, but I’m going to be bringing this out and won’t be cooped up in the room… but I will go to a storefront.

Having a physical workplace that is outside of his home would allow Derek to have more interaction with customers, which is the aspect he likes most about working at the farmers’ market. Having a storefront would allow him to sell directly to customers year-round, rather than solely when the farmers market is operational. At the moment, Derek is working on expanding the business by approaching a local grocery store chain to see if they will stock and sell his product. When asked about hiring more employees, Derek saw that as part of the business expanding into the future. He would like to hire, and has actually been approached by parents who are trying to find work for a young adult with a disability, but Derek’s business does not currently have the capacity for it.

For Julie, desire for growth is also limited by concerns about the capacity to sustain it due to her health and competing demands for time and energy. Julie wants to keep her business local
because “It’s a lot easier to keep it in one place so it doesn’t cause chaos.” Although, she would like to expand so as to have her jewelry sold in stores:

Julie: ….after I make enough jewelry, I can actually sell my jewelry probably in one of the downtown stores and probably the café would work because they have a little jewelry display there.

When asked if she wants to see her business grow she said, “Yes, I want to see how far I can get.” The emphasis that Nathan, Derek, and Julie place on having their product sold at a physical location is interesting. It was spoken of as if that would give their business legitimacy, being included among other products – an allegory for community integration.

Heather’s approach to growth for her business is different from the others in that the emphasis is less on hiring employees and more on sustaining partnerships, working cooperatively. In helping other people with ID find their voices and become self-advocates, she would like to see self-advocates start businesses either on their own or working with her social enterprise. Both Heather and Derek were working on actively growing their business, while Nathan and Julie were waiting due to management barriers they were experiencing. However, neither Heather nor Derek had a strategy for growth that would have been provided by a business or marketing plan.

c. **Innovation and idea generation**

The social entrepreneurs with ID in this research had to have been principally involved in the development of the idea for their business in order to qualify for participation. Accordingly, some of the questions asked during the interview focused on understanding their idea and how it came about and overlaps with motivation as an outcome of both interest and opportunity. For Nathan, Heather, and Julie the idea started as a hobby: something they enjoyed doing, which later became a business when people began offering to pay for it. For Derek, while the idea that he could start a coffee business was generated by his uncle,
Derek took ownership of the idea, began learning more about coffee and fair trade, and began developing the business and social mission. Heather had a similar experience in that it was her mother’s idea to begin presenting at her IEP meetings, which coincided with her growing interest in public speaking and self-advocacy. For both Heather and Julie, future planning was used as a tool to develop the idea and social mission in line with their goals for the future. Overall, learning more about the subject of the business and the social issue at the heart of it led the social entrepreneurs with ID to take ownership of the idea.

So what exactly makes their social enterprise innovative? For Nathan and Julie, the artisanal nature of their business made it unique. Nathan creates original coffee flavors and Julie creates original jewelry. Additionally, for Julie and Heather, their public speaking businesses are unique because they are sharing their personal stories and experiences. What makes Derek’s business distinct is his emphasis on freshness of the product. Yet, it is important to note that what makes the social enterprise unique is not necessarily what makes it innovative. One could argue that the way the participants have organized their business to work with the services and supports available is innovative, but again, this is not necessarily what makes the social enterprise innovative. Rather, it seems the innovative aspect of the social enterprise comes at the intersection of the social mission and meeting a market need. Nathan identified a need for fair trade, organic, flavored coffee in both decaf and regular varieties. Derek identified a need for “better than fair trade,” freshly roasted coffee. Heather identified a need for speakers with personal experience in inclusive education and skills in public speaking. Julie identified a need for storytelling and original jewelry that raised awareness about people with disabilities and service animals.
With regards to their innovation in working within the systems and supports available, that is a quality that makes them entrepreneurs. Paired with their interest in taking action via business creation to address social issues, this qualifies the participants with ID as social entrepreneurs.

2. **Outcomes and key support**

Comparing the responses of the social entrepreneurs with ID and their key support persons reveals several fascinating points of agreement and disagreement regarding self-sufficiency, profit, growth, innovation, and social mission (Tables VIII and IX). The key support persons all recognized the social mission of the business, although as discussed previously there were some differences in how they perceived it. The key supports also agreed there was innovative potential in the businesses, however, here too there is some incongruity concerning what innovation entails. For the key support persons, the innovative aspect of the business involves the social entrepreneurs’ disability. On the one hand, this may be because social entrepreneurship itself is an innovative employment strategy. On the other hand, the key supports make a connection between the social entrepreneurs’ ID and the marketability of the product/service:

James: [Nathan’s] story is really inspirational and people are really eager when they hear what he’s doing to buy his coffee or at least help him out. He tells people what he’s doing and creates evangelists just by telling what he’s doing. It’s really a grassroots effort and people get excited about it.

Charlie: It gives people the opportunity to see another person’s story and use [Derek’s] as an example to live their own lives. He’s come through so much and he doesn’t even think of his accident. He’s inspirational and inspiring to people and to me definitely.

Mary: People say it’s so inspirational and it changed their life, they wanted to try person-centered planning for their students, that kind of stuff… you gave us hope for our child…. This isn’t a typical business owning type of thing. [Heather] isn’t selling, she’s just selling her thoughts and inspiration.
Lisa: For the speaking business, [Julie’s] her message inspires people, there’s no doubt about that. She’s been an inspiration to us since she was adopted…. Now, with all these health issues that come with her type of [physical disability], she’s put up with so much and yet the glass is always half full. It’s a message of perseverance and hope and it’s an inspiration to other people. The jewelry is the same. It comes with a message of inspiration. The people who meet her want her jewelry and something that’s she made. It’s like a little piece of her they can take away which is a huge powerful thing. She’s here for a reason…

The key support persons acknowledge the social entrepreneurs’ skills and talent, yet draw upon overcoming and inspiration narratives to explain why people want to pay for the product/service.

There was a discrepancy among three of the key support persons regarding the extent to which the social entrepreneurs with ID understand what “profit” means:

James: I don’t think he’s worried about making a lot of money as long as he has his needs met which he does at the moment.

Charlie: I don’t think it was for profit. I think it was for satisfaction

Lisa: It doesn’t matter to her or us either if we’re making money.

During the interviews it was clear that making a profit meant something, even if it did not conform to a conventional definition, and that it was important to participants with ID in achieving their goals. At the most fundamental level Nathan and Derek understood a profit would allow them to keep making ethically-sourced coffee; Heather understood a profit would allow her to keep speaking and working with self-advocates and others towards the goal of inclusive education; and Julie understood a profit would allow her to keep speaking and making jewelry in a way that would help the service animal program. Further, the social entrepreneurs with ID understood that if the business did not make a profit (i.e., enough money) the business would end and they would have to try another, less desirable, strategy for employment where they still might not make enough money to support the lives they want to live. In short, making a profit means being able to keep working. The confusion among key support persons may be due to beliefs regarding skills in managing money and finances rather than an understanding of
TABLE VIII
CRITERIA FOR PARTICIPANTS WITH ID

<table>
<thead>
<tr>
<th>Participant</th>
<th>Goal of Self-Sufficiency</th>
<th>Profit-Oriented</th>
<th>Growth-Oriented</th>
<th>Innovation</th>
<th>Social Mission</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nathan</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Derek</td>
<td>Y&lt;sup&gt;3&lt;/sup&gt;</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Heather</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Julie</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Kimberly</td>
<td>Y</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;2&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;2&lt;/sup&gt;</td>
</tr>
<tr>
<td>Andrew</td>
<td>Y&lt;sup&gt;3&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>Wayne</td>
<td>Y&lt;sup&gt;3&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;2&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

1. Refers to social enterprises that employ people with ID, but that are not owned or run by them.
2. Refers to enterprises being started by people with ID that do not have a social mission.
3. While not a goal of the business itself, it appears to be a personal goal.

TABLE IX
CRITERIA FOR KEY SUPPORT PARTICIPANTS

<table>
<thead>
<tr>
<th>Participant</th>
<th>Goal of Self-Sufficiency</th>
<th>Profit-Oriented</th>
<th>Growth-Oriented</th>
<th>Innovation</th>
<th>Social Mission</th>
</tr>
</thead>
<tbody>
<tr>
<td>James (Nathan)</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Charlie (Derek)</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Mary (Heather)</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Lisa (Julie)</td>
<td>Y&lt;sup&gt;3&lt;/sup&gt;</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Deborah (Kimberly)</td>
<td>Y</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;2&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;2&lt;/sup&gt;</td>
</tr>
<tr>
<td>Sylvia (Andrew)</td>
<td>Y&lt;sup&gt;3&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
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<tr>
<td>Bill (Wayne)</td>
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<td>Y&lt;sup&gt;2&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Y&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

1. Refers to social enterprises that employ people with ID, but that are not owned or run by them.
2. Refers to enterprises being started by people with ID that do not have a social mission.
3. Depends on how self-sufficiency is defined. Does not necessarily mean financially self-sufficient or living independently, but rather being as independent as possible with support.
profit. The social entrepreneurs with ID all expressed the need for support in this area, but one’s skill in accounting should not be conflated with their entrepreneurship.

3. **Outcomes and Budding Futures**

Kimberly, Andrew, and Wayne were not principally involved in the creation or development of the idea for Budding Futures. Further, it was not their idea to start working there. It was their parents’ idea and they agreed it would be a good idea. However, they did not seem to take ownership of the idea, but rather they continued to look for other opportunities more in line with their interests. In addition to being in the start-up stages of a business venture, Kimberly also works at a Goodwill retail store and Wayne has several volunteer positions, working at a grocery store and an office position at a local athletics department. Like Kimberly and Wayne, Andrew also has employment as a janitor at a local community college in addition to his work at Budding Futures. When asked which job they enjoyed more, despite enjoying working there, none of them choose Budding Futures. Their key support persons had difficulty choosing which job their family member with ID enjoyed most, but they were aware that Budding Futures was probably not their favorite. One possible explanation for this is that the participants with ID at Budding Futures are going through a transition stage of their lives where they are exploring their interests and skills as well as the options available.

a. **Income, profit and self-sufficiency**

The participants with ID working at Budding Futures differed from the social entrepreneurs with ID in that they all had a goal of becoming self-sufficient and this goal was clearly identified by their key support persons. Their employment at Budding Futures played an important, but limited role in working towards this goal. The job served as a vehicle for earning the work credits they needed and as an important source of income. Once the work
credits were obtained, the job became superfluous and employment better matched to their skills and interests was desired. Similar to the social entrepreneurs with ID, becoming “self-sufficient” was spoken of by the participants with ID as a desire for independence and self-determination. Kimberly, Andrew, and Wayne all currently live at home with their families. Kimberly is hoping to move into her own place and live with friends. Wayne would also like to live on his own someday, but it is “unclear” if that will happen in the next five years. Notably, it was when Andrew was asked whether he had ever thought of being self-employed when he first mentioned an interest in pursuing postsecondary education:

**Interviewer:** Have you ever thought about starting your own business or being self employed?

Andrew: If I go to college I could probably live there and start my business there.

**Interviewer:** Have you thought about it before? Is it something you want to do?

Andrew: I’m thinking if I go to college or not.

This raises a question of whether and to what extent postsecondary education decisions influence employment decisions, particularly as regards self-employment, entrepreneurship, and social entrepreneurship. It is possible a college or university environment could provide the support, resources, opportunities, and service coordination needed to make social entrepreneurship a viable option for people with ID – essentially serving as a business incubator.

Where the concept of “self-sufficiency” differed from the social entrepreneurs with ID is that it was closely tied to having a source of earned income paying minimum wage or more. This remained true for Kimberly and Wayne, who are in the start-up stages of entrepreneurship.

Kimberly: I like getting paid. I like having money in real life too, for stuff, clothes, food. And if I want to get a place, to pay for rent. I’m just thinking ahead.

Wayne: It’s money I get to put into my bank account. I love getting a check and when I ride to the bank I feel happy when I have it in my hand. I earned it from my hard work…. To do anything in this world, you need money. It’s important to feel like you’re being
appreciated for your work and what better way to appreciate someone than give them a paid position somewhere. Paying them and saying here’s your check is saying they appreciate your work.

While Kimberly and Wayne intend for their business to make a profit, they do not intend to depend upon profit from the business as their sole source of income. The participants with ID working at Budding Futures explained that making money was important to them. There is a belief that making money will allow them to live the lives they want. Receiving a paycheck also connotes an appreciation for their work and is something they take pride in. While Wayne does not see a difference in the work he does at his paying job versus his volunteer jobs, he wishes he was paid for all of his work. Part of the reason Andrew likes his work at the community college more than at Budding Futures is because it pays more. Kimberly likes the work that she does at Goodwill, but wishes they were not cutting back on personnel so that she could have more hours and be paid more.

b. **Advancement and growth**

Budding Futures does not employ people with disabilities in management or leadership positions. Subsequently, there are limited opportunities for advancement among the individuals with ID working there. For example, Andrew has been working at Budding Futures since its inception and his expertise in his current position was acknowledged by the management staff during research recruitment as well as by his key support person. Over the course of the interview, he revealed an interest in becoming a professional gardener. Yet, when asked if he ever wanted a management position at Budding Futures he replied, “I think that’s for the staff at the greenhouse.” There is currently no mechanism in place for employees with ID to advance within the organization. Moreover, if someone were promoted from the position of “Team Member” to a leadership or management position, there might need to be a change in payment as well as the membership fee requirement. In fact, the current organizational structure
may be blocking advancement and limiting the potential for people with ID to be integrally involved. If the mission of the social enterprise is to provide work experience and skill development for people with ID in an integrated environment, then this practice appears to diverge from their purpose – undermining the social mission. It bears consideration the extent to which the work arrangement at Budding Futures qualifies as integrated employment if it is inclusive, but not equal.

For Kimberly and Wayne, it was not important to be in a management or leadership position at Budding Futures; perhaps because they did not have an expectation of promotion. However, a desire for more control (e.g., being the boss and making decisions) was one of the motivating factors behind wanting to start their own business. At one point, Wayne wanted to be more involved in the selling aspect of the business at Budding Futures, and Kimberly expressed an interest in being more involved in retail and running the cash register. It seems likely that these interests were discouraged by the way the organization was structured, sensing the limited potential for involvement. In the new start-up venture, Kimberly is taking a leadership role, drawing upon her strengths in organizing and planning events. Wayne wants to take a management role, tapping into an interest in office work and taking responsibility for helping his friends work together effectively.

For all of the participants with ID and their key support persons, it was important that there be a good fit between interest, skill, and employment. Although, for participants working at Budding Futures, fit was spoken of in reference to future employment. For participants pursuing social entrepreneurship, fit had been a motivating factor in choosing the employment pathway they were on. This is indicative of the effect that the relationship between motivation and job satisfaction have on employment outcomes. Yet, the outcome measurements that are
used to assess wage or salaried employment fall short of capturing the full picture with regard to
social entrepreneurship. Delving into the structural environment within which outcomes are
determined can provide insight into better understanding why.

B. **Structural**

Within disability research and policy the terms self-employment and entrepreneurship
have been used interchangeably (Yamamoto et al., 2011) without providing information to
determine the extent to which operational definitions correspond to theoretical definitions
(Parker Harris et al., in press). Distinguishing entrepreneurship from self-employment is
essential to discussion on how to improve labor force participation for people with disabilities.
Only 16.9% of self-employed people in the U.S. hire any employees (Henley, 2005; Hipple,
2004). At the same time, new, small businesses create most of the new jobs in the economy
(Birch, 1987; Kane, 2010; Neumark, Wall, & Zhang, 2011). This job creation happens mostly
by those new enterprises that provide innovative, novel solutions to the marketplace, thus
responding to real consumer needs (Shane, 2008). When building sustainable employment
strategies, the establishment of new businesses by people with disabilities is key. However,
simply encouraging businesses for self-employment will have little effect. Self-employment has
limitations as an anti-poverty strategy given it is intended to employ one individual. The scope
of self-employment is not large enough to make an impact on unemployment. In contrast, due to
the potential for both business and job creation, entrepreneurship can be an effective strategy for
addressing unemployment and poverty. This indicates a discontinuity in policy and practice
pertaining to the stated benefits that entrepreneurship hopes to achieve (Parker Harris et al., in
press).
1. **Outcomes in disability employment**

Within the broader context of disability employment, successful outcomes refer to individuals who have gained and retained integrated and competitive employment. Accordingly, a variety of variables are used to indicate employment outcomes for people with disabilities including, *inter alia*: the number of individuals served; the percentage employed; average annual earnings; average weekly work hours; and the percentage with high school diploma/GED (Sulewski, Zalewska, Butterworth, & Migliore, 2013). The precise data collected depends largely upon the data source. For example, outcomes collected by the Rehabilitation Services Administration (RSA) include total number of closures in VR, rehabilitation rate, percentage employed, average weekly earnings, and average weekly work hours. Alternatively, the employment outcomes collected by the National Core Indicators (NCI) include total reporting, percentage in integrated employment, two-week work hours, and two-week earnings. Simply put, it is difficult to compose a comprehensive picture of the current state of disability-entrepreneurship in the U.S. because we are not collecting statistics on it. The closest approximation of statistics reflecting the entrepreneurial environment for people with disabilities must be cobbled together from a variety of sources that address the issue peripherally (Parker Harris et al., in press).

For the most part, rates of incorporated and nonincorporated self-employment remained unchanged between 2010 and 2011. Compared to nonincorporated self-employed workers, incorporated self-employed workers were more likely to work in management and professional occupations and have higher employment outcomes such as full-time, year-round work, health insurance, and higher income earnings (Layne, 2013). Additionally, the amount of home-based workers has increased significantly over the past decade and self-employed workers account for
nearly half of those who work primarily from home (Mateyka, Rapino, & Landivar, 2012). While informative, this data does not take disability into consideration as a demographic characteristic. As a result, we do not know whether workers with disabilities who are self-employed and/or work from home follow the same trends as the general population. In 2011, the Current Population Survey found that the national self-employment rate for persons with a disability increased from 10.7% the previous year to 11.8%. For the general population without a disability, the self-employment rate was significantly lower and showed little change, decreasing slightly from 6.8% in 2010 to 6.6% (Bureau of Labor Statistics, 2011, 2012).

In 2009, an analysis of self-employment outcomes within the federal and state VR system was published (Revell et al., 2009); serving as a snapshot reflecting self-employment as it exists in the VR service system for the period from 2003 to 2007. Interestingly, a recent analysis of outcomes for this same time period delves into further depth; identifying gender, ethnicity, cost of VR services, education attainment, and public supports as predictors of successful closure in self-employment (Yamamoto & Alverson, 2013). In 2007, the percentage of case closures in self-employment nationally was 1.7%; however, there was a large degree of variation between states, with four states reporting percentages over 5% (Maine, 6.0%; Alaska, 6.6%; Wyoming, 7.9%; and Mississippi, 12.6%). This sizeable variation is indicative of differences between states in the services and support available (Revell et al., 2009). Further, this data still provides very little information about social entrepreneurs with ID, many of whom may be operating outside of the VR system.

Disability employment outcome measures as they pertain to entrepreneurship do not appear to fully reflect entrepreneurship in practice – lacking ecological validity and speaking instead to a fragmented system of employment services (Parker Harris et al., in press). While
case closure in self-employment can perhaps be an effective measure for determining successful entry, our research has found that, when it comes to social entrepreneurship, it stops short of capturing the full picture (Parker Harris et al., 2013). Entry is only one aspect of entrepreneurship, beyond which lies firm growth as well as financial and operational success (Venkatraman & Ramanujam, 1986). It is important to support people in thinking beyond merely establishing a business, to thinking of the business in terms of growth and innovation. To truly consider the issue of disability employment from a perspective of social entrepreneurship we need to reassess what outcomes are representative of social entrepreneurship as an ongoing process rather than as simply a static moment.

2. **Outcomes in entrepreneurship**

According to the Global Entrepreneurship Monitor Social Entrepreneurship Study, the U.S. has the highest prevalence of early-stage social entrepreneurship activity (Lepoutre, Justo, Terjesen, & Bosma, 2013). Recent advancements in entrepreneurship have undergone an international effort to improve the quality of data and outcomes through the establishment of standardized entrepreneurship indicators, intended to inform policymakers of how the implemented policies affect entrepreneurship and objectives for the economy and society (OECD, 2009). In the case of social entrepreneurship, this necessitates addressing both economic and social outcomes (Austin et al., 2006; Mair & Martí, 2006; Zahra, Gedajlovic, Neubaum, & Shulman, 2009), whereas traditionally there has been a tendency to prioritize economic outcomes over non-economic outcomes (Haugh, 2006).

Entrepreneurial outcomes have been described as “a desired level of activity or performance, which specifies the intended effects, achievements or consequences of supplying a service to targeted recipients” (Haugh, 2006, p. 181). Outcomes in social entrepreneurship can
be conceptualized as economic outcomes, social outcomes, and environmental outcomes. They can also be direct or indirect. The permutations of social entrepreneurial outcomes therefore comprise a complex matrix of direct economic, social, and environmental outcomes and indirect economic, social, and environmental outcomes occurring at the individual level, at the enterprise level, and at larger societal levels. Measures of outcomes in entrepreneurship are utilized to facilitate management processes. Subsequently, outcomes will vary between enterprises using different strategies that require different information (Haugh, 2006). Bridging the priorities of disability employment and social entrepreneurship therefore requires identifying outcomes that will be both useful to social entrepreneurs with ID in managing their business as well as to policymakers and practitioners in determining the appropriate provision of services and supports.

What is needed in disability employment is a shift away from research and practices that focus narrowly on self-sufficiency. Policy is needed that understands and encourages innovative, growth-oriented entrepreneurship by people with disabilities, leading to hiring of others who may also have disabilities. The conflation to date has been particularly problematic given the difficulties that arise in interpreting entrepreneurial outcomes when referred to by closures in self-employment or statistical self-employment prevalence (Parker Harris et al., in press).

C. **Reification**

The outcomes of social entrepreneurship for people with ID need to be assessed at various stages and will differ depending upon where they are in the business development process. In other words, the way that an individual is participating and supported in their social entrepreneurship (regardless of whether or not they have a disability) will change as they progress from the idea development stage to entrepreneurial entry, and will continue to change as they move from start-up development to growth and so on. Currently, only entrepreneurial entry
is being measured in disability employment, and this is being accomplished by rates of “successful” VR case closure in self-employment (Parker Harris et al., 2013). However, the social entrepreneurs with ID in this research are operating largely outside of the VR system and are not reflected in measures such as the 42 cases closed in self-employment in Illinois in 2012 at 0.79% of the agency total, compared to a national average of 2.13% (RSA, 2012). This data reflects only self-employment for people with disabilities who were able to use the VR system to gain successful entry into employment. Accordingly, we really do not know how many people with ID are pursuing self-employment, entrepreneurship, and social entrepreneurship. Further, many people with disabilities pursuing these customized employment strategies may be working independently or using job supports that are provided by service agencies, but not necessarily for the expressed purpose of business development. For instance, recall that Nathan’s Job Coach is provided through a customized employment program. Nathan had a different Job Coach before he began working with James (Nathan’s key support person). However, this initial Job Coach was not an entrepreneur and was limited in the type and amount of support they could provide. It is likely that there are more social entrepreneurs with ID like those participating in this research who are piecing together a patchwork that relies upon existing services to provide entrepreneurial support due to a lack of access or information regarding entrepreneurship-specific training and programs. It also bears consideration that the majority of the participants in this research were multiply employed, in both paid and unpaid work. The rate of VR case closure in self-employment fails to capture the employment activities of such individuals or reflect an accurate picture of the current employment landscape.

In 2012, those individuals closed in self-employment in VR reported having worked an average of 22 hours per week in Illinois, compared with 28.06 hours per week for the national
average (RSA, 2012). Research has found that the average entrepreneur works 47.7 hours per week during the start-up phase and 63 hours per week during growth stages (Mueller et al., 2012). The social entrepreneurs interviewed here worked on their business much less due to the time constraints of their supports, sometimes as little as six hours a week. Additionally, existing employment outcomes do not capture the experiences of people with ID who are multiply employed, working in both paid and unpaid positions.

There are indications that people with disabilities who are self-employed make higher average weekly earnings (Revell et al., 2009). Those individuals who had successful self-employment case closures in Illinois reported an average hourly earnings of $12.96 ($13.85 nationally). This is much higher than the average hourly earnings for individuals employed in an integrated setting both with supports ($9.20) and without ($10.56). The earnings in self-employment are also much higher than the minimum wage in Illinois is $8.25 per hour and the federal minimum wage, $7.25 (Table X). That said, the average hourly earnings for people with cognitive disabilities in Illinois VR was only $9.36 in 2012, with a marginal increase to $9.46 nationally (RSA, 2010). When discussing social entrepreneurship, the term “wage” can be somewhat misleading as entrepreneurship is typically an alternative to wage or salaried employment (Kolvereid & Isaksen, 2006). The earnings of the social entrepreneurs with ID interviewed in this research varied considerably. For Derek, the income from his business changed seasonally and was much higher when the farmers market was operational. Julie’s income has been much lower as she and her support person have slowed the work pace due to her health concerns. Also, Heather’s income varies depending upon who is paying; Heather may make between $300 to $1,000 for a keynote speech, but will also work pro bono if it is for an
organization that has provided her with services in the past. Nathan’s income from his business also changes seasonally, offering more flavors during the holidays.

TABLE X

HOURLY WAGE COMPARISON

<table>
<thead>
<tr>
<th></th>
<th>Illinois</th>
<th>National</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimum Wage</td>
<td>$8.25</td>
<td>$7.25</td>
</tr>
<tr>
<td>Self-employment*</td>
<td>$12.96</td>
<td>$13.85</td>
</tr>
<tr>
<td>Employment without supports in an integrated setting*</td>
<td>$10.56</td>
<td>$11.53</td>
</tr>
<tr>
<td>Employment with supports in an integrated setting*</td>
<td>$9.20</td>
<td>$8.82</td>
</tr>
<tr>
<td>Cognitive impairment*</td>
<td>$9.36</td>
<td>$9.46</td>
</tr>
</tbody>
</table>


Overall, information regarding hourly, weekly, or annual earnings for the social entrepreneurs with ID in this research was not available because it was not collected. Ideally, it would have been helpful to contextualize the data gained by knowing how much profit their business made versus how much they were paying in expenses. Further, it would be helpful to know how much of their expenses were paid out-of-pocket, how much were financed by business activities, and how much were supported by public or grant funding. Collecting this information would help in answering questions such as, what would be the real costs to Nathan if he wanted to hire his Job Coach, James (Nathan’s key support person), as an employee? Moreover, how much profit would a social entrepreneur need to make in order to “get off benefits” and what exactly would this entail? To what extent might not using public benefits and
disability services harm their business and/or their livelihood (e.g., affecting access to housing, paratransit, and healthcare)?

The main problem being faced is that there are not structures in place to allow for the kind of employment outcomes wanted/expected from social entrepreneurs with ID. Their businesses are expected to make a profit, and yet people with disabilities are structurally disadvantaged in saving and asset accumulation, contributing to the pervasiveness of asset poverty (Parish, Grinstein-Weiss, Yeong Hun, Rose, & Rimmerman, 2010). Some efforts have been made to enable asset development for entrepreneurs with disabilities (K. Harris & Weinberger-Divack, 2010), however, many social entrepreneurs with disabilities do not know these programs exist (Parker Harris et al., 2013). Further, little is known about how people with ID can use programs such as IDAs if they are not in control of their own finances, or if the program is not accessible to people with intellectual impairments (Soffer, McDonald, & Blanck, 2010). Instead, it seems people with ID who want to develop assets and savings use special needs trusts. That is, if they are aware of them; the participants with ID and key support persons working at Budding Futures were not. Regardless, these special needs trusts require social entrepreneurs to concede control of their account to a guardian. There is a great need for evidence-based best practices in entrepreneurship and social entrepreneurship for people with ID, doing so in a way that is self-determined and interdependent, acknowledging the important role of formal and informal supports.

It would also be constructive to incorporate employment outcomes that will be useful to social entrepreneurs with ID, not just to policymakers and service providers. Doing so requires expanding upon the definition of “self-sufficiency” conventionally used in disability employment, which underlies and substantiates the traditional-expectation barrier (Walls et al.,
2001). In moving forward, we need to think beyond outcomes as simply direct monetary profit as a marker for success. Social entrepreneurship is a relational process and there are many forms of profit that are indirect and nonmonetary. The next chapter draws upon these findings to interrogate the notion of “success” in disability employment.
VIII. DISCUSSION AND CONCLUSION

The “American Dream” is a work ethic that offers the promise of social mobility, often through the development of small businesses that allow individuals formerly marginalized and disadvantaged to have a better quality-of-life. New paternalism extended this discourse to reinforce the ideology of bootstrapping: pulling one's self up (out of poverty) by their bootstraps. It is not simply that if one works hard enough they will succeed, but rather if one wants to succeed they must do so without aid, in the interest of being self-reliant. Within our culture of liberalism, the emphasis on self-reliance has become ingrained as a social responsibility. It is an act of citizenship that touches upon various facets of our belief system, including how independence is often conceived of for people with disabilities. This ideology fails to recognize the social and institutional barriers facing people with disabilities and other disadvantaged populations. It falls short of taking into consideration the interconnectedness/relationality of society, and the value of interdependence in achieving independence and self-determination. If we are to challenge this hegemonic bootstrapping mentality, then we must also challenge the meaning of success itself to explore other ways of conceptualizing success reflective of a Disability Studies ideology.

Pursuant to the exploratory nature of this qualitative approach, the findings of this research are not generalizable to all social entrepreneurs with ID. Rather, they provide a foundation for future research and the development of policy and best practices informed by the experiences of people with ID who are actively engaged in social entrepreneurship.

A. Success and Failure

Significant effort has been expended to establish that starting a business (e.g., self-employment, entrepreneurship, or microenterprise) can be a viable employment option for
people with disabilities. This concept of “viability” is contingent upon individuals and service providers being able to achieve successful employment outcomes. But what exactly does “success” mean within the context of social entrepreneurship for people with ID? The traditional-expectations barrier that entrepreneurs with disabilities encounter indicates a conflict with how success is traditionally defined. Previous researchers have proposed that, for people with disabilities, success for a new microenterprise may not mean growth so much as achieving self-sufficiency and being able to claim financial independence (Walls et al., 2001). In the current research, however, this was not the case. The social entrepreneurs with ID interviewed wanted to make a profit and for their business to grow. While profit and growth are certainly connected to the concept of success, they are not what defined success for the social entrepreneurs with ID. Neither was financial self-sufficiency. Rather, success was spoken of by participants as still being in business and working towards achieving their mission(s).

Support persons may have a different idea of what success entails. For support persons, success may be just the act of entrepreneurship itself: being productive, doing something they enjoy, having social interactions and interpersonal relationships, and affording individuals with ID to have the “feeling of success.” However, among support persons the connection to profit and growth necessary for the business to continue was largely absent. This is problematic because it can create a conflict of interest in how support is provided. Key support persons that were involved in the business as an employee or business partner did make a strong connection with their customers, expressing that customer service and satisfaction were indicative of success for the business.

In an effort to identify possible outcomes, the social entrepreneurs with ID were asked two questions about what their business does for them personally as well as for others.
Participant responses were reflective of their perspectives on success, but also appear to relate strongly to their direct and indirect social mission. The direct mission is related to what their business does for others and the indirect mission is related to what their business does for them, personally. Success, therefore, is movement towards achieving those missions. Social entrepreneurship research has found that the degree to which a social venture achieves its goals is one of three criteria for success. The other two criteria comprise the acquisition of necessary resources for maintaining operations to ensure program/service provision and having the amount of resources available to grow and develop the business (Sharir & Lerner, 2006), both of which are necessary for achieving the social entrepreneurs’ goals.

Often “success” is seen as the equivalent of “not failing,” reinforcing a reductionist dichotomy wherein success and failure are mutually exclusive. However, the entrepreneurial theory of effectuation appreciates a plurality of viable options given the set means and contingencies (Sarasvathy, 2001). An entrepreneur who employs effectuation will necessarily have a plurality of failed firms for every successful one. Not only are success and failure not dichotomous variables, but they are actually interdependent – success of one option depends upon the failure of others. A similar sentiment was expressed by the social entrepreneurs with ID who resisted making a causal relationship between entrepreneurial behavior and success or failure. Instead, social entrepreneurship meant opening the door to the possibility of several options, some of which may be successful. Failure was equated to not trying, which would result in not having options available. It therefore becomes critically important to understand why social entrepreneurs with ID act (motivation), how they act (management), and what happens when they act (outcomes).
B. Next Steps in Motivation

This research indicates that social entrepreneurs with ID are motivated by many of the same factors that motivate social entrepreneurs in general, such as a desire to help society, closeness to the social problem, and a nonmonetary focus. However, these motivating factors are inextricably influenced by the social construction of disability. That is, by the social entrepreneurs with ID’s experience as a person with a disability (physical, intellectual, and/or psychological) and by the socio-cultural and political-economic barriers attendant. Disability may manifest directly or indirectly through the development of one’s social mission.

Social entrepreneurs with ID were motivated by both push and pull factors, but placed greater value on the pull factors. The participants with ID who are working at a social enterprise (Budding Futures), but who are not themselves social entrepreneurs were also motivated by both push and pull factors. However, this motivation did not appear to be as strong. In talking with the social entrepreneurs with ID about their businesses, there was a sense of excitement and a drive for the future, both for themselves and for their business. Conversely, the conversations with participants with ID working at Budding Futures were indicative of the transitory nature of the position and relatively noncommittal. Participants with ID working at Budding Futures were motivated to earn work credits and then to move on to more desirable employment, signifying the role that pull factors play in motivation for seeking other employment, including entrepreneurship as Kimberly and Wayne demonstrate.

In moving forward with social entrepreneurship as an employment option for people with ID, it is essential to bridge the divide between the approach to entrepreneurship policy and the approach to disability employment policy. Motivation has served as a key component in determining these approaches to policy development. While disability employment policy has
focused on providing equal opportunity by addressing the barriers identified by push motivations to support necessity-based entrepreneurship, entrepreneurship policy has focused on stimulating the economy by leveraging pull motivations to promote growth and innovation through opportunity-based entrepreneurship. Entrepreneurship policy should take into consideration the barriers affecting people with disabilities in employment and in entrepreneurship in particular.

More importantly, this research indicates a need for an ideological shift in disability employment policy away from focusing on push motivations and necessity-based entrepreneurship, towards an approach that integrates pull motivations and promote an environment to facilitate opportunity-based entrepreneurship. Doing so would mean not simply looking to entrepreneurship as a last option for people with disabilities who are unable to find other work, but recognizing the potential for people with disabilities to act as social innovators.

Subsequently, implementing social entrepreneurship as an effective employment strategy would require policy that 1) addresses the barriers identified by push motivations in addition to 2) facilitating and incentivizing pull motivations to 3) employ not only the individual, but also to 4) sustain a business over time that 5) has the potential to create jobs for others with disabilities and 6) address a social problem/need in the community.

Regarding areas for future research, there is a need for research on motivation in employment for people with ID across various types of employment, including but not limited to social entrepreneurship. This includes longitudinal research on motivation for entrepreneurial entry, business creation, growth, and entrepreneurial persistence. Specific to social entrepreneurship, research is needed to explore the influence of normative social structures on social entrepreneurs with ID and how that affects their motivation and the development of their social mission. Additionally, it would be interesting to examine how others perceive the
missions of social entrepreneurs with ID; whether and to what extent a stigmatized charity-model is ascribed to their business. Finally, future research should focus on exploring the motivations of various support persons and key stakeholders and, in particular, how they affect the entrepreneurial decisions of people with ID. Concomitantly, a person-centered approach to social entrepreneurship for people with ID should be developed to act as a guideline for people with ID and their support persons in pursuing social entrepreneurship.

C. **Next Steps in Management**

Despite the conflation in terminology, it has been established in previous research that self-employment, microenterprise, and entrepreneurship can be a viable employment strategy for people with ID. But it is unclear how, exactly, this is being done: what services and supports people with ID use and what barriers are encountered in starting and running a business. Previous research has established that social entrepreneurs with disabilities may operate outside of the service system for both VR and small business development because they find it inaccessible or unable to meet their needs as a business owner or as a person with disabilities, respectively (Parker Harris et al., 2013, 2014). To an extent, a similar phenomenon can be seen among the social entrepreneurs with ID interviewed here. There was substantially less effort to engage with small business development services among the participants and key support persons. There was also less engagement with VR services for the purpose of business development, but a consistent reliance upon services as a source of formal support; raising questions regarding what services are being used and how they are being used. For all of the participants with ID and their key support persons in this research, the use of SSI/SSDI and Medicare was depicted as necessary. Participants espoused a safety-net mentality predicated upon the message that people with ID needed to qualify for and obtain those services even if they
did not need to use them in the future. The use of a Job Coach and/or Personal Assistant was instrumental for the social entrepreneurs with ID interviewed. This was true even for Heather and her business partner/key support person, Mary, who suggested that PA services might be an option for Heather in the future should more support be needed or should Mary’s availability to provide support change.

In contrast to the social entrepreneurs with ID interviewed who appeared to be trying to limit or control their involvement with service systems, the participants with ID working at Budding Futures were embedded within a system of employment and transition services that seemed to almost dictate their short-term employment decisions. The participants with ID at Budding Futures and their key support persons espoused an investment mentality to these particular services, wherein sacrifices in short-term employment would hopefully lead to having greater control and choice in future employment, over the long-term. The social entrepreneurs with ID benefitted from employment that was more customized, person-centered, flexible, meaningful, and they took a more self-directed approach to service use. Further research is needed to determine whether the employment of social entrepreneurs with ID is more or less integrated or gainful than other work arrangements.

Informal supports were essential to starting a business and were essential to the management of the business for three of the social entrepreneurs with ID: Derek, Heather, and Julie. Family and friends often took on roles providing needed business services. In this way, the informal support network became formalized; mobilizing resources and opportunities in order to support the social entrepreneurship of the individual with ID. This raises two concerns, the first being that individuals in informal support networks may lack the knowledge or information necessary to adequately provide business services and support. The second concern
is that people with ID are having to rely upon their informal support networks for business services instead of VR or small business development services. This raises the question of whether this is a “real” choice (i.e., where there is more than one viable option), or whether it is because those other service systems are inaccessible and do not meet their needs? While further research is warranted, the findings from this research suggest that it is the result of the latter. It is important to note that the social entrepreneurs interviewed enjoy working with their family and benefitted from having a social support network. Accordingly, to an extent, the social entrepreneurs do choose to work with their family and friends, or in Nathan’s case to stop working with them if they feel it necessary to advancing their business. However, the social entrepreneurs’ options for obtaining needed services and supports are constrained by the barriers they encounter. Subsequently, accommodations and business support needs are met by using a combination of formal and informal supports rather than by implementing a business organizational structure that would meet these needs (Table XI).

<table>
<thead>
<tr>
<th>Need Identified</th>
<th>Associated Position in Business</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Need help understanding profit/cost, supply/demand, financial planning, identify investors and funding sources.</td>
<td>• Chief Financial Officer (CFO)</td>
</tr>
<tr>
<td>• Need help managing money, accounts, and taxes/benefits.</td>
<td>• Accountant</td>
</tr>
<tr>
<td>• Need help managing day-to-day operations of the business.</td>
<td>• Chief Operations Officer (COO)</td>
</tr>
<tr>
<td>• Need help with legal aspects of the business, certification, and compliance.</td>
<td>• Lawyer</td>
</tr>
<tr>
<td>• Need help understanding the market, identifying and reaching customers.</td>
<td>• Marketing Manager</td>
</tr>
<tr>
<td>• Need help with daily tasks, reminders, scheduling, and time management.</td>
<td>• Personal Assistant, Administrative Assistant, Executive Assistant</td>
</tr>
</tbody>
</table>
Hiring employees to fill positions was spoken of by the social entrepreneurs with ID as something to do in the future, once the business has began to make enough profit, rather than as an integral component of start-up development. This poses a dilemma as filling such positions may be necessary in order to begin making a profit, particularly given how they relate to need for accommodation. An organizational structure such as those used in the IAMC could bridge this intersection in a way that is person-centered.

There may also be a need for a business incubator for social entrepreneurs with ID. The social entrepreneurs with ID interviewed here expressed difficulty with not having access to a physical space to conduct business activities outside of their home or service provider, which impinged upon their autonomy and affected business decisions. Early on in the disability-entrepreneurship literature, it was suggested that a university-related business incubator would be beneficial to facilitating entrepreneurship among people with disabilities (Braddock & Bachelder, 1994; Burkhalter & Curtis, 1989, 1990). A business incubator for social entrepreneurs with ID would be particularly useful because it would allow the provision of support, opportunity, peer mentoring, technical assistance, and shared resources.

Moving forward, there is a critical need for further research to develop policy and evidence-based, best practices in entrepreneurship and social entrepreneurship for people with ID, particularly with regards to addressing the barriers that are encountered. With regards to the social and economic barriers experienced, there is a need for funding opportunities that are available to social entrepreneurs with ID. There is also need to address the barriers to developing assets and savings. This includes improving access to and the accessibility of financial literacy programs and resources, providing business-related financial literacy for people with ID and their supports. In particular, asset development programs are needed that are
accessible to people with ID while allowing for increased control and supported self-determination in their financial management (e.g., ABLE accounts). Additional research should identify areas where discrimination occurs for social entrepreneurs with ID. In this vein, it would be beneficial to demonstrate that people with ID can be social entrepreneurs and provide examples of how people are doing it. To address traditional expectation barriers, future research should focus on identifying training and support needs to establish evidence-based, best practices both for the individual with ID and for their supports. There is also a need to better understand what the expectations are and how these compare with traditional expectations in disability employment, which overlap with the findings regarding outcomes that follow.

In this research, it made sense to expand upon the low-readiness barrier to include readiness not just in starting a business, but also for growth over time. In addressing the barriers to business startup from readiness perspective, there is a need for accommodations in the business certification and licensing procedure for people with ID. There is also need for affordable and accessible business planning and education for people with ID, in particular around financial management, human resources, and marketing. Given that social entrepreneurs with ID and their key supports are making creative use of existing disability-specific planning strategies, it would be constructive to incorporate those methods into the business planning process so they can be used purposefully by people with ID. In this way, the business plan can be adapted to both address the business-specific concerns, but also address the disability-specific concerns. For example, it would be beneficial for social entrepreneurs with ID to develop a plan for business-related access and accommodation needs. Also, to address barriers in support it would be beneficial to develop a plan for business-related support needs and allocate resources accordingly. This may include establishing roles and responsibilities for family members within
Many of the systemic barriers have been mentioned in overlapping areas. For example, in making sure that appropriate accommodations are provided in business certification and licensing. Also, the need to address policy concerns with regards to asset limitations and disincentives, such as the fear of losing one's public benefits or healthcare if one is successful in social entrepreneurship. However, there is also a need to better understand how transition affects social entrepreneurship. More specifically, research should look at barriers and facilitators in transitioning from the child service system to the adult service system, particularly as regards employment services and the role that the IEP process is playing in the entrepreneurial decision. Further there should be a focus on educating service providers and schools about social entrepreneurship for people with ID, as these stakeholders influence entrepreneurial decisions and may be responsible for providing resources that social entrepreneurs with ID rely upon.

D. **Next Steps in Outcomes**

Given contemporary advancements in approaches to disability employment, there may understandably be some confusion over what qualifies as a “traditional” outcome or expectation. Social entrepreneurship challenges the outcomes conventionally conceived of in employment. Social entrepreneurship requires thinking beyond hiring, retention, and weekly/annual wage to thinking in terms of monetary and nonmonetary profit, growth, and innovation. For the social entrepreneurs with ID in this research, profit held significant meaning. It was not synonymous with financial self-sufficiency or income, but rather social entrepreneurship was a vehicle for achieving self-determination in employment. Making a profit meant that the social entrepreneurs with ID interviewed could continue doing work they were passionate about to the benefit of
themselves and their community/society. Growth involved expanding one’s market to reach new customers and hiring employees to increase the size and capacity of one’s business. The perspectives of social entrepreneurs with ID on growth are affected by many of the barriers experienced; readiness, financial, and support barriers in particular. As a result, growth was conveyed as something that would happen in the future after the business began to make a profit rather than as an integral part of a business and/or marketing plan that would lead to profit. This finding speaks to the need for increased access to entrepreneurial training and education. Interestingly, growth was also conveyed through a desire for their products/services to have a physical location (e.g., storefront or carried in local stores) and web presence (e.g., business website or via social media) – creating a place for themselves. Within the disability context, entrepreneurial success is dependent upon societal reciprocity: what is viewed as legitimacy or being legitimized by others (De Clercq & Honig, 2009). Having one’s products/services included among others’ in the public domain (and open market) would serve to validate the social entrepreneur with ID’s business. This has particular significance given the role that the history of institutionalization and segregation played in motivating the social entrepreneurs with ID and the impetus to distinguish business ownership from a hobby. In discussing innovation, there was a need to distinguish between social entrepreneurship as an innovative employment strategy and what makes the social enterprise itself innovative. This conflation was problematic among key support persons in particular; shifting the focus of the business away from the social entrepreneurs’ motivation and putting their social mission at risk of co-optation. Looking at the larger picture it appears that understanding profit and innovation are essential to assessing self-determination, and understanding growth is essential to assessing community integration and social participation.
Current outcome measures gauge the point of entrepreneurial entry and occasionally “retention” in the sense of business survival. There has been some discussion about sustainability of the business over the long-term, but there has not been much discussion regarding profit beyond self-sufficiency, growth beyond self-sustainability, or innovation beyond the innovativeness of such employment strategies. As explained previously, innovation refers to the creation of something new or establishing new ways of doing things and what is needed now, to complement the implementation of innovative employment strategies, is innovation in how outcomes in employment are evaluated and measured. Yet, concepts like profit, growth, and innovation seem difficult to measure or evaluate. It is here that engagement with research in entrepreneurship should prove helpful, providing a guideline for going forward in identifying outcomes that will be useful to researchers, policymakers, service providers and other supports, and to social entrepreneurs with ID themselves. It bears consideration whether there is a possibility of developing a process for evaluating and measuring outcomes in employment for social entrepreneurs with ID that generates useful information, which can then be used by those individuals to help sustain and grow their businesses. Doing so has the potential to make a substantive impact as an antipoverty strategy that empowers people with ID as change agents on a social and economic level. Better understanding motivation and management will help in determining appropriate and effective outcomes in social entrepreneurship for people with ID. In this effort, the findings of this research establish an informed foundation for future research.

E. Conclusion

At one point or another, all of the participants with ID in this research considered self-employment. Kimberly and Wayne are in the process of starting a venture that may or may not lead to social entrepreneurship. It is entirely likely that social entrepreneurship may be the
format their business takes over time, but at the moment they are still very much in the brainstorming and planning phase. During recruitment for this research, several individuals who were pursuing self-employment and entrepreneurship responded from throughout Illinois and the surrounding states. There was one memorable young woman from Michigan who started a microenterprise because she had been living in a nursing home and wanted to live independently. Starting her first business allowed her to raise enough money that she could afford to move into an apartment with a friend. After being successful in making that move, the first business ended and she wanted to start a new business that would reflect the next step in her life. It is still to be determined whether or not people with ID are more likely to choose social entrepreneurship than commercial entrepreneurship due to their experience with social problems and unmet needs. However, what this research establishes is that people with ID can and do choose to pursue social entrepreneurship. For Nathan, Derek, Heather, and Julie, social entrepreneurship was about more than having work to do or a job. In a sense it was about more than having employment that was meaningful, self-determined, and gainful. Rather, social entrepreneurship was about being a business owner – owning and creating something – being empowered to act on a social issue that has marked their lives and making their mark on the world.

People with ID are often depicted as passive recipients of care and services. However, they also have the potential to act as social agents, driven by a desire to enact one's citizenship through social and economic participation. The participants with ID in this research depict a future for themselves wherein they are both active and passive citizens. Indeed, the one relies upon the other, corresponding with how independence relies upon interdependence. Their key support persons depict a future where, while they are overwhelmingly hoping to instill a sense of active citizenship or to facilitate social agency, the citizenship of the participant with ID is
viewed as an inevitably passive one. Active citizenship is portrayed by key support persons not simply as a responsibility, but more so as an ideal that would connote membership at the social and economic level.

However, from a Critical Disability Studies perspective, the promotion of ideals can be harmful if it imposes expectations of normativity (Davis, 2006a) that would require individuals with disabilities to somehow be “less disabled” to participate in society and the economy. Tanya Titchkosky touches upon this in introducing the idea of the abled-disabled, whose “participatory power is tied to an ability to conform to normal society” (Titchkosky, 2003, p. 517). She highlights that people with disabilities find themselves in a paradoxical situation wherein citizens with disabilities are being included as an excludable type. Titchkosky makes this claim because she worries that overemphasizing exclusion and not critically focusing on the exclusionary practices within inclusion itself is dangerous. For example, there are exclusionary practices within the organizational structure of Budding Futures that undermine its social mission of inclusion, but that were instituted in an effort to be more inclusive than existing work arrangements; calling into question the innovativeness of approaches to social entrepreneurship that reframe the margins of exclusion rather than removing them.

The establishment of ideals is particularly problematic if tied to one’s expectation of “success” given that ideals represent an unachievable status that one strives towards, in which case “success” would not result in achievable or measurable outcomes. For the participants with ID, “success” was not a static ideal, but rather it was a relational process, socially constructed through interdependence. While social entrepreneurs with ID may have idealized goals and dreams for the future, “success” is not contingent upon the realization of these ideals. Instead, “success” is reliant upon having the opportunity and freedom to pursue one’s mission(s), given
the provision of adequate services and support. In this vein, the process of “success” is reflective of the interaction between active and passive citizenship.

Among all of the participants in this research, the notion of passive citizenship is predicated upon a need for group differentiated rights to identify the needs and barriers specific to people with ID that must be addressed in order to achieve equal opportunity and access. Conversely, expressions of active citizenship conferred a desire for the recognition of universal rights. These findings regarding the complex relationship between debated dichotomies in citizenship highlight an area that merits further attention in citizenship research and theory. In particular, if passive and active citizenship are interrelated, so that one depends upon the other, and group differentiated and universal rights are antecedents respectively, does that then indicate there exists an interdependent relationship between group differentiated rights and universal rights? If so, that would signify that barriers in one would affect the expressions of rights and citizenship in the others and would have a limiting effect on self-determination.

This research contributes to advancing our knowledge in disability employment and Entrepreneurial Studies by exploring how people with ID are participating in social entrepreneurship in Illinois in the current socio-political climate. The implementation of Illinois’ Employment First policy will catalyze change in how people with ID are participating and supported in employment across the state. Segregated work arrangements and sheltered workshops will hopefully become a thing of the past as more people with ID move into competitive, integrated employment. Nevertheless, this shifting employment landscape highlights the need to be speculative about how “social entrepreneurship” is being applied. Specifically, regarding how resources and funding are being allocated to support social
entrepreneurship as an employment strategy for people with disabilities at the local, state, and federal level.

If social entrepreneurship is to become an effective customized employment strategy for people with ID, then it is vital the experiences and perspectives of people with ID be included in the development of disability employment policy and programs. Most importantly, disability employment policy in this area needs to be person-centered and not based on normative assumptions of independence and self-sufficiency. Within the field of intellectual disability research and practice there is a need for deeper understanding of what social entrepreneurship entails, distinguishing it from self-employment and hobbies. Drawing upon the findings of this research in addition to those of the larger research project (PTI) in doing so will improve the quality and accuracy of the information, resources, and support that are being provided. Finally, entrepreneurship research, policies, and programs need to meaningfully engage with disability; looking beyond stigmatized perceptions of impairment to acknowledge the larger social and institutional barriers that disadvantage social entrepreneurs with ID in the marketplace. Moreover, the field of social entrepreneurship would benefit greatly from recognizing that people with ID are more than the recipients of an antiquated charity-model approach to business. Rather, people with ID have unique knowledge generated through their experiences as a person with ID in a society wherein they are marginalized and disadvantaged. As a result, people with ID have the potential to become social innovators and agents of social change.
APPENDICES
APPENDIX A

STAGE I: PRELIMINARY INTERVIEW WITH ENTREPRENEUR WITH ID

Hello [insert name], thank you for agreeing to this interview. My name is [insert name] and I am [insert title] at the University of Illinois at Chicago. As you can see from the informed consent sheet that was sent to you, this research focuses on social entrepreneurs with intellectual and developmental disabilities. This interview is being recorded so that a transcript can be made; however, your answers will be private and we will not share anything about just you with anyone outside our research team. Do you understand everything I have said? Do you have any questions before we begin? We can begin the interview now.

Talking Point: Background Information

- Demographics

Talking Point: General Impression of Experience in Entrepreneurship

- Would you like to tell me about your business?
  - How did it get started? How did you come up with the idea for the business?
  - What was your role in starting the business?
  - What is your role now in the business?
  - Do you enjoy your work?
- What was your goal/mission when you started the business?
  - Has it changed since you started the business?

Talking Point: General Impression of Supports

- Are you supported in starting and running your business? If so, how?
  - Identify the key support person.

That brings me to the end of my questions; do you have anything else you want to say? Thank you for your time today and please feel free to contact me or any member of the research team if you have any questions or concerns.
Hello [insert name], thank you for agreeing to this interview. My name is [insert name] and I am [insert title] at the University of Illinois at Chicago. As you can see from the informed consent sheet that was sent to you, this research focuses on social entrepreneurs with intellectual and developmental disabilities. This interview is being recorded so that a transcript can be made; however, your answers will be private and we will not share anything about just you with anyone outside our research team. Do you understand everything I have said? Do you have any questions before we begin? We can begin the interview now.

Talking Point: Entrepreneurial Motivation: “Why They Act?”

- Why did they start their business?
  - Did they start it because it was something they really wanted to do (pull motivation) or because there were no other options (push motivation)?
- What was their goal/mission when they started the business?
- Has their goal/mission changed since they started the business?

Talking Point: Entrepreneurial Management: “How They Act”

- How did they start their business? Did they have a plan?
- What was their role in starting the business?
- What were the main barriers/facilitators they have faced in starting it?
- Do they feel that social entrepreneurs with I/DD have different (training/education/support) needs that those without a disability?
- How does their business run? What is their role?
- Are they supported in starting and running their venture? If so, how?
- What are the main barriers/facilitators they experience in running the business?
- Where would they like to see their business go in the future? Do they want to see it grow or do they like it how it is?
- Do they have a plan for the future of the business?

Talking Point: Entrepreneurial Outcomes: “What Happens When They Act”

- What does their business do for others?
- What does their business do for them?
- Do they think they are successful? How do they know when they are successful?
- What is success:
  - For them personally?
  - For their business?

That brings me to the end of my questions; do you have anything else you want to say? Thank you for your time today and please feel free to contact me or any member of the research team if you have any questions or concerns.
Hello [insert name], thank you for agreeing to this interview. My name is [insert name] and I am [insert title] at the University of Illinois at Chicago. As you can see from the informed consent sheet that was sent to you, this research focuses on social entrepreneurs with intellectual and developmental disabilities. This interview is being recorded so that a transcript can be made; however, your answers will be private and we will not share anything about just you with anyone outside our research team. Do you understand everything I have said? Do you have any questions before we begin? We can begin the interview now.

Talking Point: Entrepreneurial Motivation: “Why They Act?”

➤ Why did you start this business?
  ◦ Did they start it because it was something they really wanted to do (pull motivation) or because there were no other options (push motivation)?

Talking Point: Entrepreneurial Management: “How They Act”

➤ When you started your business, did you have a plan?
➤ What were the main problems/obstacles you faced in starting it? What helped you to start it?
➤ Do you feel people with I/DD have different (training/education/support) needs that those without a disability or with different kinds of disabilities?
➤ How does your business run/work?
➤ What obstacles are there in running your business? What helps you to run your business?
➤ What would you like to see for your business in the future?
  ◦ Do they want to see it grow/change or do they want it to stay the same?
  ◦ Do you have a plan for the future of the business?

Talking Point: Entrepreneurial Outcomes: “What Happens When They Act”

➤ What does your business do for others?
➤ What does your business do for you, personally?
➤ Do you think you are successful? How do you know when you are successful?
➤ What is success:
  ◦ For you personally?
  ◦ For your business?

That brings me to the end of my questions; do you have anything else you want to say? Thank you for your time today and please feel free to contact me or any member of the research team if you have any questions or concerns.
APPENDIX B

Are you a social entrepreneur with an intellectual disability?

Do you have a business, microenterprise, or non-profit?

If so, we want to talk to you! A research project at the University of Illinois at Chicago is interested in interviewing you about your experiences in social entrepreneurship.

Who?
You can participate if you:
- have an intellectual or developmental disability
- live in the Chicagoland area
- are between the ages of 18 and 64
- have a business or non-profit

What?
A social entrepreneur is someone who has started or tried to start a business, microenterprise, or non-profit with the goal of making a social problem better. The goal of the interview is to better understand your experience in social entrepreneurship. We will learn why you became a social entrepreneur, how you run and manage your business, and what supports help you.

Where and when?
Interviews will be held in the Chicagoland area. You will be able to choose the date and place that works best for you. There will be two interviews. Each interview will last one hour and you will be paid $30 for being part of this research.

Why?
This research is part of a project looking at social entrepreneurship as a pathway to employment for people with disabilities in Chicago. As part of our research, we are particularly interested in including the voices of social entrepreneurs with intellectual and developmental disabilities.

If you are interested, please contact Kate Caldwell by email at kcaldw3@uic.edu or by telephone at (312)996-4711. She will be able to give you more information, discuss the project with you in more detail and answer any questions you may have.
Greetings,

Thank you for contacting us about participating in an interview. You have been chosen as a possible participant. This interview is part of a research project led by Dr. Sarah Parker Harris and Dr. Maija Renko at the University of Illinois at Chicago. This project is for social entrepreneurs with disabilities. A social entrepreneur is someone who has started or tried to start a business, microenterprise, or non-profit with the goal of making a social problem better.

The goal of this interview is to better understand your experience in social entrepreneurship. We will learn why you became a social entrepreneur, how you run and manage your business, and what supports help you. Please look at the consent form attached. This form gives more information on the project. Also, it will tell you the expected benefits of taking part in it. You will be asked to sign a copy of the informed consent form before you will be able to participate in the interview. We would like to interview you two times. Each interview should last around an hour and you will be paid $30 for being part of this research. You will be able to choose a day, time, and place that works best for you.

The next step is to contact Kate Caldwell by phone at (312) 996-4711 or by e-mail at: kcallw3@uic.edu to schedule a time to meet. Included below is a reminder checklist that may be helpful. Please contact us if you have any questions.

Reminder Checklist – Don’t Forget:

1. Call or email Kate to choose a day and time to meet.
2. Look at the consent form. If you have a guardian, look at it with them.
3. Sign the consent form. If you have a guardian they must sign it too.
4. Bring the consent form with you to the interview.

We look forward to hearing from you!

Kate Caldwell
Project Coordinator
Greetings,

We are contacting you because you have been identified as a key support for someone who is a social entrepreneur with intellectual or developmental disabilities. This interview is part of a research project led by Dr. Sarah Parker Harris and Dr. Maija Renko at the University of Illinois at Chicago. This project is for social entrepreneurs with disabilities. A social entrepreneur is someone who has started or tried to start a business, microenterprise, or non-profit with the goal of making a social problem better.

The goal of this interview is to better understand the experiences of individuals with intellectual and developmental disabilities in social entrepreneurship. The interview may include topics such as why they became a social entrepreneur, how the business runs and is managed, and what supports are used and available for help. Please review at the consent form attached. This form gives more information on the project. Also, it will tell you the expected benefits of taking part in it. You will be asked to sign a copy of the informed consent form or to consent verbally before the interview begins before the interview begins. The interview should last one hour and can be done either in person or over the telephone at your convenience. You will be given $30 as compensation for your participation.

A member of the research team will be calling you in the next 10 days to discuss your participation and to schedule a time for the first interview. Also, you can contact the research team at (312) 996-4711 or by e-mail at kcaldw3@uic.edu

Thank you for your consideration and we look forward to hearing from you soon,

Kate Caldwell
Project Coordinator
APPENDIX C

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Exemption Granted

July 15, 2010

Sarah Parker, Ph.D.
Disability and Human Development
1640 W. Roosevelt Rd. Suite 436
M/C 626
Chicago, IL 60608
Phone: (312) 996-5485 / Fax: (312) 413-1630

RE: Research Protocol # 2010-0536
“Participation Through Innovation: Social Entrepreneurship as a Pathway to Employment for People with Disabilities”

Dear Dr. Parker:

Your Claim of Exemption was reviewed on June 28, 2010 and it was determined that your research protocol meets the criteria for exemption as defined in the U.S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.101(b)]. You may now begin your research.

Exemption Period: June 28, 2010 – June 27, 2013

Your research may be conducted at UIC and with adult subjects only.

The specific exemption category under 45 CFR 46.101(b) is:

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

You are reminded that investigators whose research involving human subjects is determined to be exempt from the federal regulations for the protection of human subjects still have responsibilities for the ethical conduct of the research under state law and UIC policy. Please be aware of the following UIC policies and responsibilities for investigators:

1) Amendments You are responsible for reporting any amendments to your research protocol that may affect the determination of the exemption and may result in your research no longer being eligible for the exemption that has been granted.
APPENDIX C (continued)

2) **Record Keeping** You are responsible for maintaining a copy all research related records in a secure location in the event future verification is necessary, at a minimum these documents include: the research protocol, the claim of exemption application, all questionnaires, survey instruments, interview questions and/or data collection instruments associated with this research protocol, recruiting or advertising materials, any consent forms or information sheets given to subjects, or any other pertinent documents.

3) **Final Report** When you have completed work on your research protocol, you should submit a final report to the Office for Protection of Research Subjects (OPRS).

4) **Information for Human Subjects** UIC Policy requires investigators to provide information about the research protocol to subjects and to obtain their permission prior to their participating in the research. The information about the research protocol should be presented to subjects in writing or orally from a written script. **When appropriate**, the following information must be provided to all research subjects participating in exempt studies:
   a) The researchers affiliation; UIC, JBVMAC or other institutions,
   b) The purpose of the research,
   c) The extent of the subject’s involvement and an explanation of the procedures to be followed,
   d) Whether the information being collected will be used for any purposes other than the proposed research,
   e) A description of the procedures to protect the privacy of subjects and the confidentiality of the research information and data,
   f) Description of any reasonable foreseeable risks,
   g) Description of anticipated benefit,
   h) A statement that participation is voluntary and subjects can refuse to participate or can stop at any time,
   i) A statement that the researcher is available to answer any questions that the subject may have and which includes the name and phone number of the investigator(s).
   j) A statement that the UIC IRB/OPRS or JBVMAC Patient Advocate Office is available if there are questions about subject’s rights, which includes the appropriate phone numbers.

Please be sure to:

➔ Use your research protocol number (listed above) on any documents or correspondence with the IRB concerning your research protocol.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact me at (312) 355-2908 or the OPRS office at (312) 996-1711. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Charles W. Hoehne, CIP  
Assistant Director, IRB # 2  
Office for the Protection of Research Subjects

Enclosure(s): None

cc: Tamar Heller, Disability and Human Development, M/C 626
May 15, 2011

Sarah Parker Harris, Ph.D.
Disability and Human Development
1640 W. Roosevelt Rd. Suite 436
M/C 626
Chicago, IL 60608
Phone: (312) 996-5485 / Fax: (312) 413-1630

RE: Protocol # 2010-0536
“Participation Through Innovation: Social Entrepreneurship as a Pathway to Employment for People with Disabilities”

Dear Dr. Parker Harris:

Please note that approval of this amendment does NOT include approval of Emily Langley to conduct the research as she has not completed Initial Investigator Training. After she has completed Initial Investigator Training, please submit an Amendment adding her as key research personnel.

The OPRS staff/members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research, and have determined that your research protocol continues to meet the criteria for exemption as defined in the U. S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.101(b)].

The specific exemption category under 45 CFR 46.101(b) is:

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

You may now implement the amendment in your research.

Please note the following information about your approved amendment:
APPENDIX C (continued)

Exemption Period: May 15, 2011 – May 14, 2014
Amendment Approval Date: May 15, 2011
Amendment:
Summary: UIC Amendment #1 of April 22, 2011 is an investigator-initiated amendment and includes the following:

a) The amendment builds upon the existing protocol to include people with intellectual and developmental disabilities (I/DD) in this research; adding a fifth phase of interviews. To make information about the research accessible during recruitment and during the consent process, an abridged version of the recruitment flier and consent form have been created that use simplified language. Steps have also been added to the protocol to accommodate for subjects with I/DD and their caregiver/guardian where appropriate during the informed consent process and to ensure assent of the individual with I/DD before participation begins.

b) Increase in the number of key informant interviews;

c) The addition of key research personnel who will be transcribing data from interviews and focus groups: Owen Randall

d) Amendment Application (April 12, 2011, Version #2);

e) Appendix P: Co-Investigators/Other Key Research Personnel;

f) Appendix V: Decisionally-Impaired Individuals as Subjects in Research (April 12, 2011, Version #1);

Please note the following current Investigator Training Periods and be reminded that all key research personnel must complete two-hours of Investigator Continuing Education every two years:

1) Richard Gould: August 31, 2009 – August 31, 2011

2) Anna-Maija Renko: September 1, 2010 – September 1, 2012


4) Sarah Parker Harris: March 1, 2011 – March 1, 2013


You are reminded that investigators whose research involving human subjects is determined to be exempt from the federal regulations for the protection of human subjects still have responsibilities for the ethical conduct of the research under state law and UIC policy. Please be aware of the following UIC policies and responsibilities for investigators:

1) Amendments You are responsible for reporting any amendments to your research protocol that may affect the determination of the exemption and may result in your research no longer being eligible for the exemption that has been granted.
APPENDIX C (continued)

2) **Record Keeping** You are responsible for maintaining a copy all research related records in a secure location in the event future verification is necessary, at a minimum these documents include: the research protocol, the claim of exemption application, all questionnaires, survey instruments, interview questions and/or data collection instruments associated with this research protocol, recruiting or advertising materials, any consent forms or information sheets given to subjects, or any other pertinent documents.

3) **Final Report** When you have completed work on your research protocol, you should submit a final report to the Office for Protection of Research Subjects (OPRS).

4) **Information for Human Subjects** UIC Policy requires investigators to provide information about the research protocol to subjects and to obtain their permission prior to their participating in the research. The information about the research protocol should be presented to subjects in writing or orally from a written script. When appropriate, the following information must be provided to all research subjects participating in exempt studies:
   a) The researchers affiliation; UIC, JB VAMC or other institutions,
   b) The purpose of the research,
   c) The extent of the subject’s involvement and an explanation of the procedures to be followed,
   d) Whether the information being collected will be used for any purposes other than the proposed research,
   e) A description of the procedures to protect the privacy of subjects and the confidentiality of the research information and data,
   f) Description of any reasonable foreseeable risks,
   g) Description of anticipated benefit,
   h) A statement that participation is voluntary and subjects can refuse to participate or can stop at any time,
   i) A statement that the researcher is available to answer any questions that the subject may have and which includes the name and phone number of the investigator(s).
   j) A statement that the UIC IRB/OPRS or JB VAMC Patient Advocate Office is available if there are questions about subject’s rights, which includes the appropriate phone numbers.

Please be sure to:

→ Use your research protocol number (2010-0536) on any documents or correspondence with the IRB concerning your research protocol.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact me at (312) 355-2908 or the OPRS office at (312) 996-1711. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Charles W. Hoehne, B.S., C.I.P.
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

cc: Tamar Heller, Disability and Human Development, M/C 626
APPENDIX D

University of Illinois at Chicago

CONSENT FOR PARTICIPATION IN RESEARCH

“Participation through Innovation: Social Entrepreneurship as a Pathway to Employment for People with Disabilities”

Why am I being asked?

You are being asked to be a participant in a research project about social entrepreneurs with disabilities in Chicago, conducted by a research team led by Dr. Sarah Parker Harris (Department of Disability & Human Development) and Dr. Maija Renko (Department of Managerial Studies) at the University of Illinois at Chicago. You have been asked to participate in the research because you are considered to be a key support for someone who is a social entrepreneur with intellectual and developmental disabilities.

We ask that you read this form and ask any questions you may have before agreeing to be in the research. Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Illinois at Chicago. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

What is the purpose of this research?

This research is being conducted to gain greater understanding of the experiences of social entrepreneurs with intellectual and developmental disabilities, and the supports, services and resources that social enterprises need in order to be successful. These interviews are part of a larger project focusing on the barriers and facilitators to starting a social enterprise for people with disabilities in general, what resources are available to assist individuals to start and sustain a social enterprise, as well as attitudes towards entrepreneurship and employment policies in general. Overall, the project will include a number of viewpoints, including people with disabilities, policymakers, disability advocacy/service providers, social entrepreneur organizations and financial institutions.

If you choose to participate, a researcher will interview you face-to-face or via the telephone. You will respond to questions and share your opinions and experiences regarding your involvement in supporting social entrepreneurship.

What procedures are involved?

If you agree to be in this research, we would ask you to do the following things:

- Schedule a suitable time with a researcher to participate in a one hour interview.
- Sign this consent form and return to the research team.

Approximately 20 people will be involved in this part of the research: 10 participants will be in-depth interviews with social entrepreneurs who have intellectual and developmental disabilities, the remainder will be interviewees who have been identified by those social entrepreneurs as a key support.

What are the potential risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.
APPENDIX D (continued)

Are there benefits to taking part in the research?
You may not directly benefit from participating in the research. However, the information you provide may be useful to help others in the future as it will inform research and policy on social entrepreneurship.

What about privacy and confidentiality?
No information about you, or provided by you during the research will be disclosed to others without your written permission, except:

- if necessary to protect your rights or welfare (for example, if you are injured and need emergency care or when the UIC Institutional Review Board monitors the research or consent process); or
- if required by law.

You must sign a copy of this consent form and submit it to the research team prior to participating in the research.

The interview will be audio taped and transcribed. You have the right to review and edit this. Only the research team will have access to the tapes and transcripts. The tapes will be stored in a locked drawer, accessible only by the research team, in the researcher’s office on the UIC campus along with all of the research data and records. The transcripts will also be kept in locked file cabinet, both as electronic files on a memory stick and as printed hard copies. Personal data and identities will be assigned a pseudonym when transcripts are created and the link between data and an individual’s name destroyed as early as possible. If the data is published or reproduced in any way, names will not be used and major identifying markers will be changed. When the researchers are traveling or off-campus, research documents and materials will be locked in a briefcase, accessible only to the research team. All of the research material, including audiotapes and transcripts, will be destroyed at the end of the research. When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

Can I withdraw or be removed from the study?
If you decide to participate, you are free to withdraw your consent and discontinue participation at any time. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and still remain in the study.

Who should I contact if I have questions?
The researchers conducting this study are Dr. Sarah Parker Harris and Dr. Maija Renko. A PhD student, Kate Caldwell, will also be assisting with the research. You may ask any questions you have now. If you have questions later, you may contact one of the researchers via phone or email:

- Kate Caldwell 312-996-4711 kcaldw3@uic.edu
- Sarah Parker Harris 312-996-5485 skparker@uic.edu
- Maija Renko 312-413-8237 maija@uic.edu

What are my rights as a research subject?
If you feel you have not been treated according to the descriptions in this form, or you have any questions about your rights as a research subject, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 (local) or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.
APPENDIX D (continued)

**Remember:** Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

You will be given a copy of this form for your information and to keep for your records.

**Signature of Participant**

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I have been given a copy of this form.

__________________________  __________________
Signature                        Date

__________________________
Printed Name

__________________________  __________________
Signature of Researcher         Date

__________________________
Printed Name of Researcher
APPENDIX D (continued)

University of Illinois at Chicago

CONSENT FOR PARTICIPATION IN RESEARCH

“Participation through Innovation: Social Entrepreneurship as a Pathway to Employment for People with Disabilities”

WHO CAN BE PART OF THIS RESEARCH STUDY?
We are asking you to be part of this research study if you are a social entrepreneur with an intellectual or developmental disability older than 18 years. A social entrepreneur is someone who has started or tried to start a business, microenterprise, or non-profit with the goal of making a social problem better. Look at this entire form before you decide whether or not to be part of the interview. If you have a guardian, please talk with your guardian before making a decision together about whether or not to be part of this research. It is your own decision whether you want to be part of this research or not. Your employment services will not change based on your decision. Also, you can stop being part of this research at any time.

WHAT IS THE PURPOSE OF THIS RESEARCH?
This research will help to better understand your experience in social entrepreneurship. We will learn why you became a social entrepreneur, how you run and manage your business, and what supports help you.

WHAT ARE THE RISKS AND/OR BENEFITS OF BEING PART OF THIS RESEARCH?
There are small risks and benefits to being part of this research. If you do not feel comfortable during the interview, then you do not have to answer any question you do not want to. Also, it does not cost any money to be part of the research. You will not be paid for your time.

WHAT IS YOUR ROLE?
Your role is to be part of an interview where we will meet with you and ask you questions about your experiences in social entrepreneurship.

1. Review this consent form to make sure you understand the research and your role in it.
2. If you decide to be part of this research, contact Kate Caldwell at (312) 996-4711 or kcaldw3@uic.edu. Kate will go over this consent form with you to make sure you understand everything and answer any questions you may have.
3. If you want to be interviewed, Kate will work with you to choose a date to meet with you at the place you choose. There will be two interviews. Each interview will take less than 1 hour.
4. Then, please sign this consent form and bring it to the interview. If you have a guardian, have both yourself and your guardian sign the consent form.

For questions about your rights, call The Office for the Protection of Research Subjects at 312-996-1711.

PRIVACY & CONFIDENTIALITY:
We will keep your information private and will not share anything about just you with anyone outside our research team. We will not share any personal information in this research with service providers.

I HAVE REVIEWED AND FULLY UNDERSTAND THE INFORMATION ABOVE.
I MADE MY OWN DECISION TO BE PART OF THIS RESEARCH STUDY.

_________________________________________     ________________________
Participant’s Signature     Date

_________________________________________  ________________________
Guardian’s Signature (if applicable)   Date

________________________________________               ________________________
Investigator/Key Research Personnel Signature  Date
APPENDIX E

INITIAL CODEBOOK FOR ANALYSIS OF DYADIC INTERVIEWS

<table>
<thead>
<tr>
<th></th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Motiv</strong></td>
<td>Applies to data segments that refer to the motivation of the social entrepreneurs with ID (e.g., why they act: push/pull motivation and purpose/purposefulness).</td>
</tr>
<tr>
<td><strong>MotivSupp</strong></td>
<td>Applies to data segments that refer to how the motivation of the social entrepreneurs with ID is supported or not supported.</td>
</tr>
<tr>
<td><strong>Mngt</strong></td>
<td>Applies to data segments explaining the management/managerial processes (e.g., how they act).</td>
</tr>
<tr>
<td><strong>Outcome</strong></td>
<td>Applies to data segments indicating outcomes or possible outcomes (e.g., what happens when they act).</td>
</tr>
<tr>
<td><strong>IntBarrier</strong></td>
<td>Applies to data segments indicating barriers to employment/entrepreneurship that can be characterized as internal (e.g., personality, talent, job skills, work experience, vocational beliefs, etc.).</td>
</tr>
<tr>
<td><strong>ExtBarrier</strong></td>
<td>Applies to data segments identifying barriers to employment/entrepreneurship that can be characterized as external (e.g., environmental and workplace supports, transportation, accommodations, job opportunities, discrimination, etc.).</td>
</tr>
<tr>
<td><strong>Facilitator</strong></td>
<td>Applies to data segments that explain what helps people with intellectual disabilities in social entrepreneurship.</td>
</tr>
<tr>
<td><strong>Success</strong></td>
<td>Applies to data segments that refer to success and/or failure.</td>
</tr>
<tr>
<td><strong>Entrepreneurship</strong></td>
<td>Applies to data segments that refer to entrepreneurship theory (e.g., growth, innovation, monetary profit, self-sustainability).</td>
</tr>
<tr>
<td><strong>Mission</strong></td>
<td>Applies to data segments that refer to the mission of the business (e.g., social value proposition, social problem being addressed, etc.).</td>
</tr>
<tr>
<td><strong>Family</strong></td>
<td>Applies to data segments that refer to the role of family/family members.</td>
</tr>
<tr>
<td><strong>Accom</strong></td>
<td>Applies to data segments that indicate accommodations needed or provided for intellectual and/or physical disability.</td>
</tr>
<tr>
<td><strong>DisServices</strong></td>
<td>Applies to data segments that refer to disability services used (e.g., disability benefits, IEP and transition planning, PATH planning, PA$$ planning, etc.).</td>
</tr>
<tr>
<td><strong>NatSupport</strong></td>
<td>Applies to data segments that indicate natural supports being used by social entrepreneurs with ID.</td>
</tr>
<tr>
<td><strong>Goals</strong></td>
<td>Applies to data segments that refer to the goals, plans for the future, and vision of social entrepreneurs with ID.</td>
</tr>
<tr>
<td><strong>Impairment</strong></td>
<td>Applies to data segments that refer to the role of impairment (or disability as impairment) in social entrepreneurship for people with ID.</td>
</tr>
</tbody>
</table>
## APPENDIX E (continued)

### FINAL CODEBOOK FOR ANALYSIS OF DYADIC INTERVIEWS:

<table>
<thead>
<tr>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Motiv</strong> Applies to data segments that refer to the motivation of the social entrepreneurs with ID (e.g., why they act: push/pull motivation and purpose/purposefulness) and how that motivation is supported or not supported.</td>
</tr>
<tr>
<td><strong>Mngt</strong> Applies to data segments explaining the management/managerial processes (e.g., how they act).</td>
</tr>
<tr>
<td><strong>Outcome</strong> Applies to data segments indicating outcomes or possible outcomes (e.g., what happens when they act).</td>
</tr>
<tr>
<td><strong>Barrier</strong> Applies to internal barrier data segments indicating barriers to employment/entrepreneurship that can be characterized as internal (e.g., personality, talent, job skills, work experience, vocational beliefs, etc.). Applies to external barrier data segments identifying barriers to employment/entrepreneurship that can be characterized as external (e.g., environmental and workplace supports, transportation, accommodations, job opportunities, discrimination, etc.).</td>
</tr>
<tr>
<td><strong>Success/Failure</strong> Applies to data segments that refer to success and/or failure.</td>
</tr>
<tr>
<td><strong>Entr</strong> Applies to data segments that refer to entrepreneurship theory (e.g., growth, innovation, monetary profit, self-sustainability).</td>
</tr>
<tr>
<td><strong>Mission</strong> Applies to data segments that refer to the mission of the business (e.g., social value proposition, social problem being addressed, etc.).</td>
</tr>
<tr>
<td><strong>Accom</strong> Applies to data segments that indicate accommodations needed or provided for intellectual and/or physical disability.</td>
</tr>
<tr>
<td><strong>DisServices</strong> Applies to data segments that refer to disability services used (e.g., disability benefits, IEP and transition planning, PATH planning, PA$$ planning, etc.).</td>
</tr>
<tr>
<td><strong>NatSupport</strong> Applies to data segments that indicate natural supports being used by social entrepreneurs with ID.</td>
</tr>
</tbody>
</table>
CITED LITERATURE


Boeije, H. R. (2004). And then there were three: Self-presentational styles and the presence of the partner as a third person in the interview. *Field Methods, 16*(1), 3-22. doi: 10.1177/1525822x03259228


Watson, N. (2002). Well, I know this is going to sound very strange to you, but I don’t see myself as a disabled person: Identity and disability. *Disability & Society, 17*(5), 509-527. doi: 10.1080/09687590220215148496


White, G. W., Lloyd Simpson, J., Gonda, C., Ravesloot, C., & Coble, Z. (2010). Moving from independence to interdependence: A conceptual model for better understanding


VITA

KATHERINE E. CALDWELL
1640 W. ROOSEVELT RD., CHICAGO, IL 60608 • PHONE: (312) 699-4711 • EMAIL: KCALDW3@UIC.EDU
www.kecaldwell.com

EDUCATION
University of Illinois at Chicago, Chicago, IL, August 2008 – March 2014
Doctoral Program, Disability Studies
Dissertation: “By the Bootstraps: People with Intellectual Disabilities and the Reification of Success in Social Entrepreneurship”
Advisor: Sarah Parker Harris, PhD, Assistant Professor, Disability & Human Development

University of Illinois at Chicago, Chicago, IL, January – May 2008
Non-Degree Graduate Student

University of Chicago, Chicago, IL, August 2007
Masters of the Arts Program in the Social Sciences
Advisor: Peter J. Smith, MA, MD, Assistant Professor, Developmental & Behavioral Pediatrics

Colby College, Waterville, ME, May 2004
Bachelor of Arts in Psychology
B.A. thesis I: “The Buddy Study: An Examination of College Students’ Attitudes Towards Individuals with Intellectual Disabilities”
Advisor: Joseph E. Atkins, PhD, Assistant Professor, Cognitive Science

Université de Bourgogne, Dijon, France, August – December 2000
Centre International d’Etudes Françaises (CIEF)

COMPUTER PROFICIENCY
ATLAS.ti; SPSS; MS Office Suite (Office, Excel, PowerPoint, Publisher, Access); Adobe Creative Suite (Acrobat Professional, Photoshop, Dreamweaver); Accessibility Wizard; EndNote and RefWorks; HTML and CSS; FileZilla and Fetch; integrated social media.

WORK EXPERIENCE
Research Specialist, Americans with Disabilities Act (ADA) National Network Knowledge Translation Center (ADA KT Center), Project 2: Increasing the use of ADA related research, National Institute on Disability Rehabilitation and Research (NIDRR), Present
• Providing assistance with scoping and systematic review of the evidence available in the field on the ADA.

Editorial Coordinator, Intellectual and Developmental Disabilities
American Association on Intellectual and Developmental Disabilities (AAIDD), November 2011 – Present
• Assist the journal Editor, Dr. Glenn Fujiura, in management of manuscripts and the peer-review process. Responsibilities include screening submitted manuscripts, quality control, securing peer reviewers, monitoring the review process, and diligent correspondence with authors, reviewers, and associate editors.
Project Coordinator, Participation Through Innovation, UIC Chancellor’s Discovery Fund for Multidisciplinary Pilot Research, Department of Disability and Human Development & Department of Managerial Sciences
University of Illinois at Chicago, July 2010 – July 2012

- PTI was a two-year joint project to promote collaboration between two disciplines that have never worked together before, combining the joint efforts and expertise of Dr. Sarah Parker Harris in the Department of Disability & Human Development and Dr. Maija Renko in the Department of Managerial Sciences, this project will make an indelible contribution to understanding the theoretical and policy implications of social entrepreneurship for persons with disabilities.
- Responsibilities included coordinating research efforts regarding the review of literature, community resource assessment, obtaining IRB approval, secondary data analysis of a large national dataset, participant recruitment for focus groups and interviews, qualitative data collection and analysis in addition to administrative tasks.
- Assisted in development and submission of several federal grant proposals (via grants.gov and fastlane).
- Planned and implemented a community workshop event for social entrepreneurs with disabilities.

Graduate Assistant, Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTC/ADD), University of Illinois at Chicago, September 2008 – June 2010*

- Served as a research assistant on two projects under a NIDRR funded grant requiring skills attendant to instrument design, IRB submission, database development, data entry and analysis.
- R4: Research with Dr. Tamar Heller examining the satisfaction of persons with intellectual disabilities and their families with personal assistance services through administering surveys to caregivers participating in the home-based support services program (HBSSP) in conjunction with the National Core Indicators (NCI) and interviews with consumers with intellectual disabilities.
- R7: Research with Dr. Glenn Fujiura examining the effectiveness of self-reported health measures for individuals with intellectual disabilities through cognitive interviewing with individuals with intellectual disabilities. Assistantship concluded in August, 2009.

LEND Trainee, Leadership & Education in Neurodevelopmental Disabilities, Institute on Disability and Human Development, UCEDD, University of Illinois at Chicago, 2009

- LEND is an interdisciplinary AUCD program funded through the Maternal & Child Health Bureau.
- Trainees develop a knowledge and experience base in neurodevelopmental disabilities, family-centered care, cultural competency, and leadership skills.

Part-Time Analyst, Research Pros Inc., Chicago, IL March 2008 – August 2008

- Conducted confidential contract outsourcing market analysis within the healthcare sector.

Staff Assistant, Institute for Mental Health Initiatives (IMHI)*, The George Washington University School of Public Health & Health Services, Washington, D.C. September 2004 – June 2005
* Absorbed into the School for Public Health & Health Services in July, 2005.

- Managed and directed multiple interns in updating extensive subscriber database.
- Collaborated with IMHI’s founders in the capacity of Project Manager for their Mental Health & Media speaker series, Continuing the Dialogue.
- Marketed for speaker series events without funding.
- Developed comprehensive spreadsheet for both paid and unpaid marketing options for IMHI operations.
- Redesigned information pamphlets and assisted in maintenance of web page.
- Provided basic administrative support.

College Buddy Director, Best Buddies, Colby College, Waterville, ME 2002 – 2004

- Best Buddies is an international non-profit organization dedicated to enhancing the lives of people with intellectual disabilities by providing them with opportunities for one-to-one friendships and integrated employment.
- Managed and directed college student volunteers and adults in the community with intellectual disabilities.
• Collaborated with regional Best Buddies Program Manager, faculty within Colby’s psychology department, neighboring businesses, Host Site Coordinator at local residential living facility and members of their staff to ensure our activities were sanctioned and supported within and for the benefit of the community.

• Attended national Leadership Conference in Bloomington, IN (2002) and Houston, TX (2003).

**Internship, Special Works Inc.**, June 2003 – March 2004

• Special Works was a sport-centered social enterprise started by Olympic athlete, Bob Wheeler, dedicated to the rehabilitation of children and young adults experiencing chronic illness and injury; provided by funding and in cooperation with personnel at Duke University.

• Conducted extensive literature review, using positive psychology and psychoneuroimmunology (PNI) to articulate the effects of positive mental attitude on recovery intended for use in business planning and start-up efforts.

**Internship, Dr. Richard Shapiro, M.D., P.A**, Bangor, ME January 2003

• Worked with Primary Investigator on drug trials dealing with asthma, allergies, emphysema, and chronic obstructive pulmonary disease (COPD).

• Developed a brochure about the increased risk of developing osteoporosis as a result of steroid inhaler use.

• Created a questionnaire to gauge people’s risk level of developing osteoporosis and to identify high-risk patients.

• Outlined a study to test the effectiveness of risk level system.

**Clerk, Colby College Psychology Department**, Waterville, ME September 2001 – 2003

• Provided general support for the department.

**PUBLICATIONS**


Caldwell, K. (2013). Dyadic Interviewing: A Technique Valuing Interdependence in Interviews with Individuals with Intellectual Disabilities. *Qualitative Research, 0(0)*.


**PRESENTATIONS**


**Caldwell, K., Parker Harris, S.** (2014). From Goodwill to Bad Will. Forthcoming paper presentation at the *Society for Disability Studies Annual Conference*, Minneapolis, MN.


**Caldwell, K., Lehrer, R., Coombs, R., & Heffernan, A.** (2013). Nobody’s Perfect Film Screening & Discussion. Moderator for discussion panel at the *Bodies of Work Festival of Disability Arts & Culture*, May 22nd, Chicago IL.


**Caldwell, K.** (2004). The Buddy Study: An Examination of College Students’ Attitudes Towards Individuals with Intellectual Disabilities. Presented at the Maine Psychological Association (MePA) Annual Conference, Waterville, ME.

TEACHING & GUEST LECTURES

DHD 401 – Foundations of Disability & Human Development, Fall 2011
Department of Disability & Human Development, University of Illinois at Chicago

Thinking Critically About Intellectual Disability in Disability Studies, Fall 2012 & 2013
Guest Lecture for DHD501 – Disability Studies I
Department of Disability & Human Development, University of Illinois at Chicago

Supporting Healthy Sexuality, Spring 2011
Guest lecture for the LEND Trainee Program
Illinois LEND Program, Institute on Disability & Human Development, University Center for Excellence in Developmental Disabilities,
Education, Research, and Service (UCEDD) at the University of Illinois at Chicago

AWARDS
• Chancellor’s Graduate Research Fellowship, University of Illinois at Chicago, 2011-2013
• Chancellor's Committee on the Status of LGBT Issues, Graduate Paper Award, University of Illinois at Chicago, 2011
• Ann and Edward Page-El M.D. Scholarship Award in Neurodevelopmental Disabilities, University of Illinois at Chicago, 2010
• Senior Thesis Designated as Distinguished, Colby College Psychology Department, May 2004
• Recognition of Outstanding Service, Colby College Psychology Department, April 2004
• Outstanding Chapter Award, Best Buddies Colleges, 2002

PEER REVIEW PARTICIPATION
• Society for Disability Studies Conference Proposals, 2013 & 2014
• Qualitative Research Journal, 2012 & 2013
• Journal of Homosexuality, 2011

ACADEMIC SERVICE
• Society for the Study of Social Problems (SSSP) Annual Meeting, Roundtable Organizer, 2014
• Chancellor’s Committee on the Status of Persons with Disabilities (CCSPD), Member, 2012 – Present
  • Student Advisory Committee, Chair, 2013—2014
  • Executive Committee, Member, 2013—2014
• Disability Studies Student Council (DSSC)
  • President, 2010 – 2011
  • Student Life Chair, 2008 – 2010
• Illinois LEND Trainee Liaison to AUCD Virtual Trainee, 2009

COMMUNITY SERVICE
Community Consulting, 2010 – Present
Consult with community organizations, service providers, individuals with disabilities and family members interested in social entrepreneurship. Provided information and helped connect them with resources for further information and technical assistance.
**PTI Workshop Planning**, October 2011
Planned and implemented a community workshop event for social entrepreneurs with disabilities; providing a forum through which social entrepreneurs with disabilities can interact with peers they may not otherwise have the opportunity to meet and gain access to information and resources. Responsibilities involved general event planning such as budgeting; catering; collaborating and corresponding with event speakers, sponsors, and volunteers; creating promotional and workshop materials; marketing and management of the event. This workshop event was co-sponsored by the Department of Disability & Human Development, the Department of Managerial Studies, the Institute for Entrepreneurial Studies, and Access Living.

**Chicago Disability Pride Parade**, 2009 & 2010
Responsible for planning the involvement of the Department of Disability & Human Development, the Institute on Disability & Human Development, the Great Lakes ADA Center, and the Chancellor’s Committee on the Status of Persons with Disabilities at the University of Illinois at Chicago. This city-wide event is organized in cooperation with the Disability Pride Parade Planning Committee, composed of grass-roots volunteers from various disability-related organizations and affiliations.

**PROFESSIONAL AFFILIATIONS**
- Society for the Study of Social Problems, Member, 2014
- Society for Disability Studies, Member, 2007 – Present
- Royal Society for the encouragement of Arts, Manufactures and Commerce (RSA), Fellow, 2012 – Present
- American Association on Intellectual and Developmental Disabilities (AAIDD), Member, 2012 – Present
- American Sociological Association, Member, 2012 – Present
- IDHD Disability & Sexuality Consortium, Member, 2010 – Present
- AUCD Sexual Health Special Interest Group, 2012
- Special Olympics International, World Winter Games Student Delegate, 2009
- American Psychological Association, Student Affiliate, 2001 – 2004