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**Understanding the Influence of Social Networks and Social Roles on Individuals with  
Developmental Disabilities: Providing Opportunities in Order to Assess Quality of Life**

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**Understanding the Influence of Social Networks and Social Roles on Individuals with Developmental Disabilities: Providing Opportunities in Order to Assess Quality of Life**

This study investigates the influence of social role opportunities on quality of life for individuals with developmental disabilities (DD). It also explores the impact of informal social networks on social capital for this population. This study analyzed the effects of newly created social role opportunities on quality of life for a small group of individuals with DD. The hypothesis suggested that those given a new social role would report a higher quality of life than those not given a new role. Pre-test/post-test interviews were administered and a 6 week intervention was implemented with participants of a local social group in order to assess quality of life. A Social Capital Index interview was also conducted to determine the social capital of the participants in the social group. In terms of social capital, the second hypothesis proposed that members of the social group would have more social capital than those who were not members of a social group. Results from this interview were compared to data from individuals who were not members of a social group in order to determine if informal social networks influence social capital. Nonparametric statistics were used, but no statistically significant findings were revealed. Despite the lack of significance, qualitative evidence aligns with previous literature and suggests that people with development disabilities share a common desire for more social role opportunities.

Key Words: developmental disabilities, quality of life, social roles, social networks, social inclusion, social capital

**Understanding the influence of social networks and social roles on individuals with developmental disabilities: Providing opportunities in order to assess quality of life**

Social roles are an ever present aspect of society. These roles, or “prescriptions defining what the behavior of a [societal] member should be” (Biddle and Thomas 1966: 29), include being a parent, an employee, a friend, and so forth. People strive to fulfill their social roles so that they can be accepted members of society, and this acceptance provides people with a sense of satisfaction and a higher quality of life (Bigelow et al. 1982; Schalock 1990).

Unfortunately, this acceptance into society is not guaranteed. Some people are not given their fair chance of fulfilling social roles, and therefore, have fewer opportunities to meet societal expectations. One major contributor to the lack of social role opportunities is the scarcity of opportunities to develop social networks (Cohen-Hall and Kramer 2009; Foley and Chowdhury 2007; Schalock et al. 1981). Social networks, a vital component of social capital, are the interpersonal connections that people develop which create a sense of social reciprocity (Halpern 2005). Without social networks, social roles are more challenging to obtain, resulting in an inability to meet societal standards (Condeluci et al. 2004; Forrester-Jones et al. 2006). Nussbaum (2006) explains that individuals who cannot meet societal expectations are left within the margins of society. Individuals with developmental disabilities are one group of marginalized citizens that lack these coveted social role and network opportunities.

This lack of opportunity is the inspiration for my study. Bigelow and colleagues (1982) stressed the need to consider social role performance opportunities when evaluating quality of life, and this study, incorporating that advice, aims to enhance the current literature by analyzing the effects of increased social role opportunities on quality of life for individuals with developmental disabilities. This study also examines the impact of informal social networks on

social capital for people with developmental disabilities. The connection between quality of life and social role opportunities for this population must be addressed because their lack of opportunities puts them at a disadvantage (Gardner and Carran 2005; Forrester-Jones et al. 2006). If people with developmental disabilities do not have opportunities for roles or networks, whether in employment, community activities, or personal relationships, their quality of life may be negatively impacted. My study addresses this issue by investigating the impact of social roles and networks on quality of life for individuals with developmental disabilities.

### A LACK OF OPPORTUNITY

A lack of social role opportunities hinders individuals with developmental disabilities' chances of achieving their highest potential quality of life, and further marginalizes this population. Society's perception of disability influences social role opportunities as well as the creation of social networks. We must understand the sociology of disability in order to fully comprehend the lack of opportunity for individuals with developmental disabilities. By realizing the ways in which society marginalizes this population, we can use this knowledge to address their lack of opportunities and to discover methods for increasing social role and network opportunities, therefore correcting society's marginalizing flaws.

#### *The Sociology of Disability*

Developmental disabilities are severe, chronic impairments that originate at birth or during childhood (AIDD 2000). Developmental disabilities can include impairments in language, learning, or physical capacity, and typically last throughout the individual's lifetime (e.g. Down syndrome, autism, cerebral palsy) (CDC 2016). According to the Centers for Disease Control and Prevention, in the United States, about 15% of children aged 3-17 have at least one developmental disability. This equates to approximately 1 in 6 children (CDC 2016).

There has long been a stigma associated with disability, which greatly influences the way people perceive and interact with individuals with developmental disabilities (Foley et al. 2014; Foley and Chowdhury 2007; Overmars-Marx et al. 2014; Schalock 1990). Some cultures, for example, believe that developmental disabilities are a consequence for past sins or that they are caused by a possession of spirits (Scior 2011). In regards to a more westernized perspective, the once popular Medical Model of Disability further perpetuated the stigma by suggesting that disabilities were a problem that needed to be fixed (University of Leicester 2017). By assigning the label of “problem” to disabilities, this model was consequently also labeling the *individual* with the disability. By insinuating that the disability needed to be fixed, the person became marginalized and thought of as “abnormal” in the eyes of society (Scope 2016).

Many disability theorists believed that the Medical Model was flawed because it placed the burden of disability on the person. The Social Model, a branch of the Social Constructionist Theory, emerged in direct opposition to the Medical Model and proposed that rather than trying to “fix” the person, we should try to “fix” society’s perspective on disability (Cheng 2009). According to Social Model theorists, disability is a type of oppression produced by a society that imposes restrictions on people with impairments (Foley and Chowdhury 2007). In other words, societal restrictions and barriers oppress people with impairments and prevent a supportive environment. The Social Model offers a more positive take on disability in that it is not something that needs to be treated, but rather that the status of “disabled” is a socially constructed product of the barriers that society creates. It is society, not the individuals, that creates the notion of disability because we allow for obstacles to inhibit impaired individuals. (Cheng 2009; Scope 2016). Take an individual who uses a wheelchair, for example. If there are no wheelchair ramps at a particular location, she or he will not be able to enter the building. This,

in turn, causes them to carry the status “disabled”. If there is a ramp, then this status is eliminated because society has addressed their needs and has made the particular location more accessible. Essentially, Social Model theorists argue that the actual impairment is not what causes restrictions in daily living, but rather it is the interactions between health conditions and environmental factors that contribute to the restrictions that individuals with disabilities face in their lives (Foley et al. 2014; Mithen et al. 2015). With the Social Model, we can now explore the flaws of society, rather than of the individuals.

While the Social Model attempts to highlight society’s oppressive behaviors and the resulting impact on people with disabilities, individuals with disabilities still face constant barriers in their lives (Bates and Davis 2004; Cohen-Hall and Kramer 2009; Foley and Chowdhury 2007; Overmars-Marx et al. 2014). These barriers will be more thoroughly analyzed in the discussion of role theory, but it is important to emphasize that while many theorists strive to transform society’s mentality toward individuals with developmental disabilities, much still needs to be done. The aforementioned lack of social role opportunities and social networks for this population showcases the need for more research in order for people with developmental disabilities to be treated as competent members of society with the same opportunities as typically-developed individuals. It is crucial that this lack of opportunity is addressed in order for individuals with developmental disabilities to achieve their highest potential quality of life.

#### *Quality of Life, Social Role Opportunities, and Social Networks*

In order to better understand quality of life for individuals with developmental disabilities, it is imperative to note that quality of life is a complex concept that pertains to all people, regardless of ability (Reinders and Schalock 2014). Quality of life (QOL), according to the World Health Organization, is defined as “individuals’ perceptions of their position of life in

the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (WHO 1997:1). The concept of quality of life encompasses levels of independence, social relationships, and one’s psychological state (WHO 1997). It is important to note that the literature often uses the terms “quality of life” and “life satisfaction” interchangeably (Heal and Chadsey-Rusch 1985). However, life satisfaction is typically considered the subjective component of quality of life.

The previously mentioned connection between a lack of social roles for individuals with developmental disabilities and quality of life cannot be ignored. Without the proper opportunities, they are left at a disadvantage and do not have the option to reach their highest potential quality of life (Schalock 1990). Evidence for a lack of social role opportunities for this population has been found through interviews. For instance, Gardner and Carran (2005) found that the majority of their participants lacked social roles. Interestingly, however, Gardner and Carran (2005) also found that if participants reported having a choice of the services they received, the type of residence they lived in, or the kind of work they were interested in, then they were three times more likely to report having social roles. This finding highlights the need for choice. If individuals with developmental disabilities are given more choices and opportunities, they would potentially be better able to fill social roles. Forrester-Jones and colleagues (2006) also found that participants reported a lack of opportunities to engage in community activities. This lack of opportunities translates to a lack of social roles available for individuals with developmental disabilities, which can in turn lead to a lower quality of life (Schalock 1990).

Specific social roles, such as employee or student, are challenging for many individuals with developmental disabilities to obtain. For example, the 2010 FINDS Survey, conducted by



The National Association for Retarded Citizens (NARC<sup>1</sup>), investigated employment status for 5,000 individuals with developmental disabilities and found that only 15% of the respondents were employed (NARC 2016b). Employment allows one to perform duties in order to fulfill one's contribution to society (Schalock 1990), and Schalock and colleagues (2000) found that work opportunities are positively correlated with quality of life for individuals with developmental disabilities in that if people feel that they are unable to fulfill a societal role (i.e. employment), they may feel less satisfied with their lives. In addition, Cohen-Hall and Kramer (2009) found that social involvement with coworkers contributed to increased quality of life and higher levels of life satisfaction for individuals with developmental disabilities, and that the more work-related responsibilities one was given, the higher the sense of pride one perceived. This further supports Schalock and colleagues' (2000) findings and showcases the importance for social role opportunities in various aspects of life, including employment.

In regards to educational social role opportunities, individuals with developmental disabilities age out of high school by the age of 22 in most states, leaving them to face a potentially stressful transition period (NARC 2016a). Oftentimes, their role as a student comes to a close at this age because the few college level programs offered to this population are typically very expensive (NARC 2016a). Without the proper resources and opportunities to obtain higher education, individuals with developmental disabilities are once again at a disadvantage because this lack of role opportunity hinders their chances of reaching their highest potential quality of life.

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<sup>1</sup> The use of the word "retarded" is no longer common when discussing developmental disabilities. NARC or ARC are often the terms used when discussing the organization now, so as to avoid derogatory or out of favor language.

Additionally, people with developmental disabilities are less likely to have the opportunity to transition into different roles at a given time (Gardner 2005). For example, people without disabilities perform various roles throughout the course of each day, transitioning between employee, friend, student, and so forth, but these opportunities for different social roles are less abundant for individuals of the developmental disability community. For instance, an individual with a developmental disability may not have the opportunity to fulfill the role of friend for several days at a time if their communication (Mithen et al. 2015) or transportation (Schalock 1990; Schalock et al. 2000) resources are scarce. Mithen and colleagues (2015) found a lower prevalence of both direct and indirect contact with friends for individuals with developmental disabilities, meaning that communication issues often lead to a loss of role-fulfillment opportunities regarding friendship. Additionally, many people with developmental disabilities do not own their own phones, thus making it more difficult to contact one another (Mithen et al. 2015). Furthermore, inadequate transportation options have been linked to a lack of friends as well as a decrease in quality of life (Schalock 1990; Schalock et al. 2000). People who either cannot afford public transportation or do not have the freedom to choose their mode of transportation are unable to see their friends on a regular basis; therefore once again indicating a lack of role opportunities regarding friendship.

Individuals without disabilities take the smooth transition from one social role to the next for granted. The Council on Quality and Leadership's (CQL) Social Capital Index for 1993-2006 reports that of the 6,424 participants interviewed with developmental disabilities, only 31.4% indicated performing different social roles (CQL 2007). This suggests that many participants believe they do not enact a variety of social roles (e.g. friend, active community member, employee). More important, however, is that these participants reported a desire for more

abundant and diverse social roles (CQL 2008). This highlights a lack of role opportunities despite the desire for such opportunities, which is concerning given that they contribute to a higher quality of life (Schalock 1990).

Role opportunities will continue to be scarce if we do not emphasize the importance of social networks. Social networks are a necessary component of social capital and include friends, family, neighbors, work colleagues, and so forth. (Halpern 2005). Social capital is often referred to as relationships, networks, and associations that connect people and groups together, allowing for reciprocity, which provides a means for social inclusion (Halpern 2005; Overmars-Marx et al. 2014). This capital comes in the form of “good will, fellowship, sympathy, and social intercourse” (Halpern 2005: 6). In other words, one forms social networks in order to create relationships with people who share common interests. These bonds allow for the development of trust and reliability so that when one is struggling, network members can provide comfort through sympathy or fellowship (Halpern 2005). That person is then expected to return the favor if someone in the network is in need; hence the creation of reciprocity. Bourdieu’s (1986) interpretation of social capital is most fitting for the current conversation, as he stresses the importance of social networks for the construction of social capital, but he also asserts that these social networks are neither a natural nor a social given. He proposes that people have access to varying levels of social capital, which either hinder or advance their positions in society (Appelrouth and Desfor Edles 2012: 653-660). Put differently, Bourdieu suggests that while networks are a public good, they are not distributed equitably throughout society and as a result, social capital marginalizes those who find the construction of social networks to be challenging (Mithen et al. 2015).

Individuals with developmental disabilities fit Bourdieu's description in that they struggle to build their social networks and are consequently marginalized, as a lack of social networks leads to a lack of social role opportunities. Moreover, Bigelow and colleagues (1982) suggest that every person who fulfills a social role has someone else affiliated with that role, therefore implying that people do not perform social roles independently. The term social, by definition, implies that others are involved, and that we are unable to perform social roles without influence from someone else. Essentially, while we strive to meet the standards of society, we are also striving to build our social networks. These social networks provide us with social role opportunities which then lead to higher levels of life satisfaction and happiness (Forrester-Jones et al. 2006; Halpern 2005). Additionally, it is thought that personal and community relationships are strongly related to well-being (Halpern 2005), thus further illustrating the importance of social networks in one's life.

Additionally, social capital is commonly thought of in two categories: bonding and bridging (Cohen-Hall and Kramer 2009; CQL 2005). Bonding social capital is thought to be the "glue" that holds people together with those similar to themselves and is best represented by informal social networks composed of friends, family, and people of similar characteristics (CQL 2005). Bridging social capital connects different networks together, promoting social inclusion and allowing for diverse relationships to form (Cohen-Hall and Kramer 2009).

The idea that social role opportunities result from the number of people that we know highlights the need for large social networks. While the average network size of typically developing individuals is 150 people, studies have found much smaller networks for individuals with developmental disabilities (Cohen-Hall and Kramer 2009; Condeluci et al. 2004). For example, one study found that the average network size for individuals with developmental

disabilities was 22 people, 43% of whom were paid staff (Forrester-Jones et al. 2006). With so few people in their social network, access to social role opportunities is scarce. Schalock and colleagues (1981) provided additional evidence for small social networks among individuals with developmental disabilities. They evaluated friendship patterns for 43 females and 26 males with developmental disabilities and found that females had an average of two friends and males had an average of one friend. These friends were found to most likely be roommates or paid staff (Schalock et al. 1981). These relationships with staff members are oftentimes more instructional than emotional (Forrester-Jones et al. 2006), indicating that the individuals interviewed by Schalock and colleagues (1981) are most likely lacking a true emotionally reciprocal relationship. Gardner and Carran (2005) also found that the majority of their participants reported a lack of friends. Due to the lack of meaningful relationships, individuals with developmental disabilities are highly confined in their ability to develop social networks (Robertson et al. 2001). This confinement prevents this population from obtaining social role opportunities. Since role opportunities promote happiness and increase self-esteem, confidence, and overall life satisfaction, individuals without adequate social networks are at a disadvantage (Simplican et al. 2015).

If larger social networks lead to more social role opportunities, and these opportunities are thought to lead to a higher quality of life, it is therefore imperative that everyone has the ability to develop such networks. This is challenging for individuals with developmental disabilities, and further research must be done in order to determine methods that encourage opportunity for social interaction, and in turn increased social roles. This lack of opportunity must be addressed in order to provide individuals with developmental disabilities the opportunity to reach their highest quality of life.

*Theoretical Framing*

My study's focus on the relationship between social role and network opportunities and quality of life is rooted in role theory and its relation to quality of life theory. Together, the two theories explain that, although society expects social roles to be fulfilled, not everyone has the same opportunities to fulfill these roles. Role theory discusses role performance and the numerous barriers that can block role opportunities, while quality of life theory takes this idea one step further by tying the concept of blocked opportunities to marginalized populations, specifically people with developmental disabilities.

*Role theory.* Role theory is a socio-psychological construct proposing that all individuals have certain social roles they must occupy (Biddle and Thomas 1966). The performance of the roles depends heavily on social norms in that if people do not meet the social norm or societal expectation, then the performance is thought to be poor. Alternatively, if the performance meets all social norms and societal expectations, the performance will be deemed satisfactory (Biddle and Thomas 1966). Bigelow and colleagues (1982) tied this idea to the developmental disability population when they suggested that a person's need is the ability to be satisfied with his or her life while society's need is for the person's performance to be satisfactory. It is thought that the ability to meet societal expectations is dependent upon one's cognitive, affective, behavioral, and perceptual abilities (Bigelow et al. 1982). Therefore, individuals with developmental disabilities are automatically placed at a disadvantage in terms of meeting societal expectations. This supposed give and take between society and individuals is challenging to uphold when the standard of performance does not take into consideration the abilities of all people, and this issue must be addressed because when societal expectations are met, quality of life increases (Schalock 1990).

Without the proper opportunities to satisfy societal expectations, people are left at a disadvantage. The importance of social roles is clear, yet the idea that social roles should be accessible to marginalized populations is not always upheld. The assumptions underlying social role theory are challenged when groups of people are excluded from participating in the life of the community. In order to participate, one must have the opportunity for social roles, and Foley and colleagues (2014) suggest that there are common barriers that prevent individuals with developmental disabilities from gaining access to these opportunities.

The previously discussed stigma that this population continually faces blocks opportunities and creates barriers that attempt to prevent individuals with disabilities from being accepted into mainstream society. The negative attitude of strangers perpetuates the lack of opportunities for this population (Foley et al. 2014; Scior 2011). Scior (2011) suggests that an increase in public awareness about developmental disabilities is needed in order for public attitudes to change and social inclusion to occur. This suggestion stemmed from her realization that research is extremely limited in regards to public attitudes and knowledge of people with disabilities (Scior 2011). Additionally, Yazbeck and colleagues (2004) found that students, highly educated people, and individuals who had prior experience with people with developmental disabilities exhibited more positive attitudes toward the population, while the attitude of the general public was more negative. These negative attitudes emphasize the lack of opportunities by reinforcing the barriers that individuals with developmental disabilities face.

Barriers for this population exist in many forms. Whether it is inadequate access to transportation (Cohen-Hall and Kramer 2009), meek employment options (Foley et al. 2014), a lack of inclusion in neighborhood activities (Overmars-Marx et al. 2014), or bullying, oppression, and discrimination (Bates and Davis 2004); these individuals endure a constant battle

with a society that relentlessly marginalizes those who deviate from the “norm”. The barriers that society constructs and the stigma that strangers automatically place on individuals with developmental disabilities makes an assumption that this population cannot live up to “normal” societal expectations, and as a result places expectations either too high or too low (Wright 1966). The strength of this assumption greatly hinders the potential for social role opportunities for individuals with developmental disabilities. In summary, there are many challenges in place for this marginalized population. Without proper access to social roles, social role theory weakens because it no longer represents all individuals. Research is needed to better understand how to eliminate the barriers and create more social role opportunities.

*Quality of life theory.* As an expansion of role theory, the overarching concept behind quality of life theory is to urge people to better understand marginalized individuals so that their exclusion from society is lessened and their well-being and life satisfaction can be improved (Schalock and Verdugo 2002). While quality of life, in general, is a relevant concept for all populations, quality of life theory aims to bring awareness to marginalized populations in an attempt to investigate methods for improvement. There are several core components of quality of life, and it is important to note that the components apply to all people with or without disabilities. The issue addressed in quality of life theory is whether individuals with developmental disabilities have the opportunity to satisfy all components, and therefore have the highest potential quality of life.

Quality of life theory provides a conceptual framework to better understand mental health needs and services for individuals with developmental disabilities (Bigelow et al. 1991). This framework allows researchers to evaluate service programs while taking all aspects of one’s



quality of life into account. Though the theory divides quality of life into eight domains (Reinders and Schalock 2014), the present study focuses on the domain of social inclusion.

The theory has four main premises of quality of life: 1) It is essentially the same for people with or without disabilities in that we all want to fulfill societal responsibilities; 2) It is a social phenomenon; 3) It is the product of a relationship between the individual and society; 4) It is defined by the consumer, therefore it is subjective (Schalock 1990). Quality of life is an interchange between an individual's potential to succeed in society and the societal circumstances that influence that potential (Reinders and Schalock 2014). Quality of life theory stems from this idea and closely relates to the previously discussed role theory, because it suggests that there is an unspoken social contract in which society provides opportunities, and the individual must in turn fulfill societal expectations (Bigelow et al. 1982; Bigelow et al. 1991).

The aforementioned social contract is the foundation for quality of life theory because it emphasizes the connection between the individual and society as well as the obstacles that marginalized populations face when attempting to uphold this connection. Perhaps the most vital component of this social contract is the previously discussed construction of social networks. Social networks not only allow for emotional and practical support (Foley and Chowdhury 2007), but they also provide social role opportunities and a sense of reciprocity (Halpern 2005). In other words, people depend on other people for their social role opportunities in order to fulfill their contract with society. MacIntyre (1999) supports this idea by proposing that people are always in a social debt in that we are constantly relying on the resources of others in order to fulfill our own roles, and thus we can never become truly independent. Social networks play a crucial role in upholding the social contract that quality of life theory proposes, and it is vital that

more research is done in order to develop better strategies for building networks for this population.

The link between role theory and quality of life theory is evident. The social contract proposed by quality of life theory relies on the construction of social networks and the performance of social roles. Society sets the standards that must be met in order to actively participate in the life of the community (Zatura and Goodhart 1979). If one does not have the opportunities to meet the standards, then he or she is unable to fulfill their own social roles and therefore faces a barrier that prohibits them from participating more fully in the life of the community. This lack of opportunity in turn influences one's perceived quality of life (Simplican et al. 2015). There is therefore an evident disconnect between social networks and social role opportunities for individuals with developmental disabilities. It is nearly impossible to have one without the other, and this reciprocal relationship is the core investigatory component of the social inclusion domain of quality of life theory. If individuals with developmental disabilities are included into society, then their opportunities for social roles will increase (Reinders and Schalock 2014).

Research is crucial, specifically with individuals with disabilities, in order to determine the impact that social roles, or the lack thereof, have on quality of life. Previous research has studied quality of life by interviewing residents and staff in order to evaluate the quality of life domains as a collective, but to my knowledge, research has not been done to investigate specific domains and how to improve them. Additionally, while research has been done to assess the importance of social networks for this population, little has been done to compare social capital levels between those involved in informal social networks and those not involved. Empirical research is scarce for this population, and it is my goal to bridge the gap in the literature by

providing insight into how the specific domain of social inclusion impacts quality of life by exploring the influence of social role opportunities and informal social networks.

## METHODS

My study investigates the influence of social role fulfillment opportunities on the quality of life for individuals with developmental disabilities. It also explores the impact of informal social networks on one's social capital. This study utilized a series of interviews as well as an experiment to assess the quality of life and social capital of people with developmental disabilities. Results from this study could provide further insight into how service organizations can improve programs that would incorporate more client-led activities and encourage the development of social networks. Additionally, in concert with the quality of life application principles proposed by Schalock and Verdugo (2002), this study hopes to enhance the participants' well-being, as well as to encourage a sense of control.

Throughout my investigation, I address the questions, "Do new opportunities for social role fulfillment increase quality of life for individuals with developmental disabilities?" and "What impact does the existence of informal social networks (social groups) have on social capital for this population?" The dependent variables are both subjective and objective quality of life as well as levels of social capital. The independent variables are the presence or absence of a new social role opportunity and the participation or nonparticipation in an informal social network. I made comparisons between individuals who were not given additional role opportunities to those who were given the new opportunities, and quality of life was assessed. Additionally, I analyzed levels of social capital by comparing individuals who are members of a particular informal social network to those who were not members.

Based on the abundance of evidence supporting the relationship between social role opportunities and quality of life, I predicted that the participants who were given new social role opportunities would report a greater quality of life than participants not given a new social role opportunity. Schalock and colleagues (1989) suggest that there is a positive correlation between satisfaction with resources and overall life satisfaction, supporting the hypothesis of the present study in that individuals with more resources (i.e. social role opportunities) will report higher life satisfaction. In addition, I predicted that those involved in the informal social network would report higher levels of social capital than those who did not take part in the network. This hypothesis stemmed from the plethora of literature that emphasizes the importance of social networks for one's social capital.

### *Participants*

Twenty-five adults, both male and female, from an established social group for individuals with developmental disabilities were invited to participate. The group provides an environment in which individuals with developmental disabilities are able to socialize while participating in various group activities including craft making, music therapy, or exercise, to name a few. The social group is a three hour program that meets twice a week and is sponsored by a local nonprofit organization dedicated to bridging the gap between the community and individuals with developmental disabilities. There is an age requirement of 21 in order to be a member of the social group. Members were eligible to participate in the study if they had the ability to communicate verbally. Since the literature suggests that the use of proxies in determining perceived quality of life should be avoided if at all possible due to potential inaccurate responses (Cummins, 1997), it was our aim to avoid the use of proxies for this study as much as possible, and individuals without the capacity to communicate verbally were

therefore excluded from the study. All members, however, were able to take part in the group activity (i.e. eating the snack, described below). We obtained direct measures from participants and supplemented with additional informants (i.e., staff members) who work for them for measures only when necessary or appropriate such as with the San Martin Scale (see “measures” section below). The San Martin Scale is completed by an informant and is used as an additional piece of information in order to obtain an objective quality of life assessment from an outside perspective. This is not a typical proxy situation because the informant is not attempting to speak on behalf of the participant nor does it replace information given by the participant. Rather, the informant is providing additional information that can be considered along with what the participant provides.

Of the twenty-five people invited to participate, twelve individuals, 4 male and 8 female, agreed to participate. Consent was obtained from the participants’ legal guardians, and assent was obtained from the participants. Some guardians declined to grant permission because they felt their adult child would not be able to understand and answer the questions truthfully. Of the twelve participants, one dropped from the study. For more information about participant attendance, see Table 1. The ages ranged from 23 to 64, with an average age of 30 years. Eleven of the twelve participants were white.

Members were randomly assigned to one of two groups, a “Social Role” experimental group or a “No Social Role” control group. The participants assigned to the “Social Role” group were given specific social roles to enact during a group activity, while the participants assigned to the “No Social Role” group served as the control and were not given any specific social roles to enact.

*Measures*

The participants completed a series of three interviews, and a staff member completed one questionnaire for every participant. I conducted all interviews with the participants. Two interview measures were combined to create one interview experience, while the third interview was conducted separately and at a different time. All of the measures utilized are designed specifically for use with individuals with developmental disabilities.

*Social Capital Index* (CQL, 2005) is an outcome interview given to individuals with developmental disabilities in order to measure their levels of social capital. Outcome interviews focus on whether people are obtaining the desired outcomes from their social services or supports (CQL 2015). Social service organizations use this measure to evaluate their client's social capital as well as the organization's programs in order to determine which program areas need improvement. The social capital index score represents the total number of outcomes present divided by the total number of people in the sample (CQL 2005). This study's data was compared to data from a small sample of individuals ( $n = 9$ ) who do not participate in the social group.

The interview is composed of a possible 52 questions, and is separated into eight different categories of outcome indicators. They include: People have intimate relationships (e.g. "Who is there for you when you need to talk?"); People live in integrated environments (e.g. "Where do you live/work?"); People participate in the life of the community (e.g. "What kinds of things do you do in the community? How often?"); People interact with other members of the community (e.g. "Who do you know in the community?"); People perform different social roles (e.g. "What kinds of involvement and responsibilities do you have in your neighborhood or community?"); People have friends (e.g. "With whom do you like to spend time?"); People are

respected (e.g. “Do people listen to your comments and concerns?”); People are connected to natural support networks (e.g. “Who are the people in your life that you can count on?”). If “no” or a vague answer was given for certain questions, the outcome was scored as “not present”. In addition to the overall social capital index score, the first five indicators are also grouped together in order to obtain a score for bonding social capital, and the last three indicators are grouped in order to calculate bridging social capital. Since this interview typically requires certification in order to administer, I was trained on how to conduct and score this interview by a certified staff member of the nonprofit organization in which the study took place.

*San Martin Scale: Social Inclusion Subscale* (Verdugo et al., 2014b) is an 11 item questionnaire. This questionnaire was answered by a staff member of the nonprofit organization who was familiar with the social group participants. Questions were answered based on a four point never-sometimes-often-always scale, with “never” representing a score of one and “always” indicating a score of four. A sample item for the social inclusion subscale is, “He/she has opportunities to go to other environments, different from the place where he/she lives (i.e., traveling, making trips, tourist routes, etc.)” The larger San Martin Scale (Verdugo et al., 2014b) consists of 95 items covering all 8 domains of quality of life as previously mentioned, but we focused on items 73-83, which forms the social inclusion subscale.

The social inclusion subscale served to measure objective quality of life. Previous research revealed that Cronbach’s alpha for the social inclusion subscale is .90, indicating a high level of internal consistency (Verdugo et al. 2014a). Further, Cronbach’s alphas are provided for level of disability and are as follows: mild-.89, moderate-.91, severe-.90, and profound-.91. These also indicate high levels of internal consistency (Verdugo et al. 2014a).

*ComQol-I5: Comprehensive Quality of Life Scale-Intellectual/ Cognitive Disability Fifth Edition* (Cummins 1997) provides both an objective and subjective scale in order to measure the quality of life for this population. The objective scale asks questions such as, “Do people outside of your home ask you for advice?” It allows for factual answers in order to assess objective quality of life. The subjective scale allows for the participants’ perceptions of their quality of life to be expressed. A sample question is, “How happy or sad do you feel about the things that you have? Like the money you have and the things that you own?” Previous research found that Cronbach’s alpha for this measure is as follows: the importance scale; .48, satisfaction scale; .65, importance and satisfaction together; .68. I analyzed scores for the combination of satisfaction and importance because this combination has the highest Cronbach’s alpha and therefore is the most reliable.

*LSS: Lifestyle Satisfaction Scale* (Heal & Harner, 1993) is a 45 item questionnaire regarding one’s subjective quality of life, or life satisfaction. The LSS was chosen as a measure because the literature suggests that the subjective component of quality of life is often measured through life satisfaction scales (Bigelow et al., 1982; Schalock et al., 1989; Verdugo, Schalock, Keith, & Stancliffe, 2005). Main areas of questioning include community, recreation, and job satisfaction (Heal & Harner, 1993). An example item is, “Are you happy with what you do in your free time?” An affirmative answer is scored as a positive one or two, depending on the level of enthusiasm expressed. A negative response is scored as either a negative one or two. This measure was administered in its entirety. Previous research found that Cronbach’s alpha for the LSS is .88, indicating a high level of internal consistency (Heal & Harner, 1993).



*Procedure*

The Institutional Review Board at Illinois Wesleyan University as well as the appropriate authority at the nonprofit organization approved the study, and then participants were recruited via a recruitment letter. They were given an informed consent form, as well as an assent form, and an opportunity to ask questions or address any concerns before completing the pre-tests. The informed consent and assent forms were read aloud to the participants. Participants were informed that they were able to stop the interview process or take a break at any time, and a follow-up could be provided if they so chose.

Participants also underwent an acquiescence screening as well as a competency test to determine if they truly understood what was being asked of them and to prevent response bias. The acquiescence screening included questions such as, “Do you sew all of your own clothes?” or, “Do you control who your neighbors are?” and the questions were dispersed throughout the interview. Those who answered no to these questions passed the acquiescence screening. Every participant passed the acquiescence screening. In addition to acquiescence, participants also completed a competency test before the subjective portion of the ComQol-I5. This test determined if the participants understood the subjective component of the scale by measuring magnitude as well as concrete and abstract references (see Cummins 1997 for more details). One participant did not pass the competency testing, and therefore their subjective ComQol-I5 data was removed from analysis.

Data collection began with the pre-test interviews. The ComQol-I5 and LSS were administered together in an interview format assessing the participants’ subjective and objective quality of life. The pre-tests took approximately 30 minutes for each participant to complete. Interviews were conducted in a separate room away from other social group participants to

ensure privacy. After all pre-test interviews were administered, the experiment began. Over six weeks, the participants took part in a snack making activity at the social group. While the group was familiar with occasional snack-time activities, a consistent snack activity as well as the opportunity to contribute to the activity was a novel occurrence. Participants randomly selected for the “Social Role” experimental group were assigned a role for the activity (e.g. making the snack, passing out the snack). Their assigned role varied week to week. The participants randomly selected for the “No Social Role” control group were not assigned a role, but were able to eat the snack. At the end of the multi-week experiment, the participants were interviewed again using the same measures. Participants were given a debriefing form to take with them as well as a copy of the informed consent for their records. The debriefing form was also read aloud. The San Martin Scale: Social Inclusion Subscale was completed for all participants by a staff member of the nonprofit organization both before and after the experiment for pretest/post-test purposes.

Throughout the six week experiment, all participants were also interviewed using the social capital index. This interview took approximately 30 minutes for each participant to complete. I scored the data in order to determine the absence or presence of social capital outcomes. I then compared this information to previously obtained data from clients of the nonprofit who are not members of the social group in order to determine the impact informal social networks have on social capital. Additionally, I also qualitatively coded and analyzed the data.

All information was kept confidential, and no names were tied to published data. Additionally, a staff member of the nonprofit organization was present the entire time. If a staff

member noticed distress or discomfort in any participant, they were required to notify me, and the process would cease for that individual. No distress or discomfort was detected.

## RESULTS AND ANALYSES

Data from the pre-test/post-test interviews were analyzed both quantitatively and qualitatively; data from the social capital index was analyzed qualitatively. In addition, I also documented observations from the intervention. Through this combination of data analysis, I was able to gain insight into how both social roles and social networks influence the lives of people with developmental disabilities.

### *Quantitative Analysis*

Due to the present study's small sample size and the continuous nature of the dependent variable, nonparametric statistics, specifically the Mann-Whitney U test, were utilized for this study (Cohen 2008). The Mann-Whitney U test was chosen because the difference of quality of life scores between the experimental and control group could be ranked directly and accurately, but the scores would not meet normal distributional assumptions (Cohen 2008). The Mann-Whitney U test is the nonparametric equivalent of the parametric t-test (Cohen 2008).

For the LSS, a Mann-Whitney U test indicated that the life satisfaction score for our two groups ( $U = 4.000$ ,  $p = .144$ ) was not below the critical U value. This indicates that there were no statistically significant differences between the experimental group ( $M = 3.50$ ) and the control group ( $M = 6.83$ ).

In regards to the ComQol-I5 objective measure, the Mann-Whitney U test found that the quality of life score for our two groups ( $U = 12.000$ ,  $p = 1.000$ ) was not below the critical U value, meaning that there were once again no statistically significant differences between the experimental group ( $M = 5.50$ ) and the control group ( $M = 5.50$ ). Similarly, for the ComQol-I5

subjective Importance x Satisfaction interaction, the Mann-Whitney U test indicated that the quality of life score for our two groups ( $U = 11.000$ ,  $p = .914$ ) was once again not below the critical U value. Therefore, there were no statistically significant differences between the experimental group ( $M = 5.75$ ) and the control group ( $M = 5.33$ ).

Finally, for the San Martin Scale, the Mann-Whitney U test revealed that the quality of life score for our two groups ( $U = 9.000$ ,  $p = .610$ ) was not below the critical U value, and thus indicates that there were no statistically significant differences between the experimental group ( $M = 6.25$ ) and the control group ( $M = 5.00$ ).

Despite the lack of statistically significant findings, some of the data trended in the expected direction. One post-test ranked score was lower for the experimental group than for the control group. A lower rank indicates a higher quality of life. Rankings suggested that the experimental group expressed a higher quality of life than the control group for the ComQol-15 subjective Importance x Satisfaction interaction. This information, however, should be interpreted with caution given that no significant differences were found. Additionally, although the experimental group ranked lower in the above area, this is true for both pre-test and post-test, and therefore the lower rank may not be linked to the intervention.

### *Qualitative Analysis*

Qualitative analysis was also considered because literature suggests that a dual quantitative and qualitative approach may be most beneficial when assessing a construct such as quality of life (Schalock et al. 2000). Additionally, qualitative analysis revealed various themes regarding areas in which the participants tend to lack social role opportunities. The themes of community integration, friends, living arrangement, and recreation help to explain the common aspects of life where a high quality of life might be lacking.

The experimental group observations below help provide context as to what the intervention was like. They illustrate the importance of modification when working with individuals with developmental disabilities, and also help provide knowledge about planning activities for this population.

*Experimental group observations.* The first week of snack making was somewhat chaotic. We made kabobs with ham and cheese on pretzel sticks, and we quickly learned that this was more of a challenge than expected: tearing cheese was an arduous task, and the ham stuck together, making it challenging to pull the correct amount apart. For some, the motor skills needed to get the pretzel through the cheese and ham was too advanced. Though the first week of experimentation was a bit discouraging, this was an important realization because it allowed me to improve my strategy for providing social role opportunities for people with developmental disabilities. I simply needed to modify the tasks and find a way in which I could provide a role opportunity without creating stress. By the next week, I had developed a more organized system utilizing a method closely resembling an assembly line. I chose trail mix as the next snack because it would not present an obstacle for the participants with slower motor skills. Everyone was able to participate by scooping an ingredient into a cup. The task was stress-free, and the participants each had roles that they felt comfortable accomplishing. This philosophy aligns very closely with the aforementioned Social Model (Cheng 2009) because rather than trying to “fix” the participants, I instead addressed the challenges that the original snack created. By modifying the snacks, I eliminated the idea of the disability, and everyone could then partake in the activity without any distress. If we can learn to modify our behaviors and work to eliminate the idea of disabilities, more social role opportunities may become available to this population.

Additionally, during a separate activity, one of the participants told me, “I really like helping with the snacks!” She told me this spontaneously. Other participants also explained that they enjoyed the snack making as well. Though data from our study does not reach statistical significance, we gained knowledge about the lack of social role opportunities through the perspectives of our participants.

*Social Capital and Social Networks.* After comparing this study’s social capital index data to that of the comparison data, I found that this study reflected a higher social capital index (72%) than the comparison group (51%). The large discrepancy highlights that the participants who are members of the social group seem to have a higher level of social capital than those who do not belong to the social group. This is not surprising given that social capital is often referred to as the networks that connect people together; therefore those who form networks, such as through the social group, perhaps feel more connected with other people and in turn have more social capital (Halpern 2005; Overmars-Marx et al. 2014). In addition, members of the social group also scored higher on both their bonding and bridging scores compared to those who are not members (Table 2). This may suggest that the social group produces higher levels of bonding social capital, meaning that the group encourages a close, informal network. This aligns with CQL (2005) because bonding social capital is thought to initiate the connections between peers, and the social group’s purpose is to create such connections. Though these findings might be suggesting a difference in social capital between people involved in social groups and those who are not involved in social groups, extreme caution must be used due to the small sample sizes when comparing this study’s data with that of the comparison group. A sample size of nine for a comparison is quite small, and thus the large discrepancy between the two groups may not accurately express the difference in social capital scores. Future studies should attempt to obtain

comparison data from a larger sample. Despite this small comparison group, we are still able to discuss potential reasons why this study's social capital scores are higher.

Bridging social capital scores are perhaps higher because the social group promotes community involvement and interaction. While the social group always meets at the same location, community members frequent the group; volunteering, teaching lessons in health, instructing yoga, or providing music therapy. Such a connection between the social group and the community may provide participants with a sense of belonging to their community. However, though the participants of this study reported higher bridging social capital scores, this finding should be considered with caution. Five of the eleven participants indicated that they will not talk to people they do not know within the community unless they have to. Moreover, ten of the eleven participants reported that they depend on their parents for information regarding community activities, and six of the participants said they enjoyed spending time with their parents as opposed to friends. This suggests that while the participants may do activities within the community, they are heavily dependent on their parents or other immediate family members. By being so reliant on their family members, the participants may not be as connected with other community members. Finally, ten of the participants also indicated that they do not know about other community opportunities. Perhaps this reliance on family members is also linked to Mithen and colleagues' (2015) findings that communication with people outside of the home is challenging, and as a result, the participants are unable to learn of community events. Participants may feel that relying on family members is the most logical for them given their resources. If the participants are unaware of opportunities and lack the ability to communicate with others outside of their home, they are at a disadvantage because they will miss out on events, clubs, and so forth, which could potentially increase their social network, and in turn

increase their quality of life (Forrester-Jones et al. 2006; Halpern 2005). Therefore, the participants' bridging social capital, or the formal ties that they develop with their community, may not be as great as the numbers imply.

*Lack of social roles.* As is consistent with CQL (2007) findings, in my study, only four participants indicated that they were performing social roles. Put differently, seven of the participants felt that they did not have any kind of responsibility within their community and did not feel that people depended on them for any particular reason. Three of the participants listed employment as their reason for performing social roles, and one participant listed her household chores as her social role responsibility. It is surprising that only three participants reported their job as a social role, because five of the participants reported having a job during the other interviews. This may suggest that the other two participants do not see their roles within their workplace as responsibilities. They may not realize that people depend on them for their work. Alternatively, they may also think of work and social roles as two different concepts, and therefore not consider work a social role. All participants reported that their jobs make them feel important, which aligns with previous literature in that work opportunities are positively correlated with quality of life (Schalock et al. 2000) and work-related responsibilities are positively correlated with a sense of pride (Cohen-Hall and Kramer 2009). There might be a disconnect, however, between how they feel about their job and what they perceive others to feel about them in the workplace. One participant no longer had her job during the post-test interview. Alternatively, another participant got a job between the time of the pre and post interviews.

We must take note of these findings because they highlight the participants' perceptions rather than solely focusing on an outsider's perspective. For example, if one of the participants is



absent from the social group, she or he will be missed and the other members will most likely ask where she or he is. Though this may be true, if the participant who is absent does not realize that they are missed, they do not understand the value of their role within their social group. Staff or family members may understand the participants' roles within the social group, but unless the participants themselves realize the importance of their roles, the outcome is not present. The eight previously mentioned outcomes capture the connections people have with one another, and these connections are an indicator or measure of social capital (CQL 2005). Presence of these outcomes contributes to higher levels of social capital, and the more connections or networks we build with people, the more enhanced our lives are, leading to a higher quality of life (CQL 2005). If these individuals are not reporting certain outcomes, then the services and support, either formal or informal, are lacking in some way. In order to perceive a high quality of life, one also must perceive the components that constitute a high quality of life (CQL 2005; Reinders and Schalock 2014). It is crucial that we determine methods for creating a sense of role fulfillment in order to enhance individuals with developmental disabilities' chances of achieving their highest potential quality of life. My experiment offers one model for how this may be achieved.

*Community integration.* The results for the outcome indicator "People live in an integrated environment" express another interesting finding. All eleven participants reported an outcome for this indicator and all but one indicated during the post interview that doing activities with people outside of the home is important, but five of the participants only suggested the social group as their form of integration into the community. Since every participant is a member of the social group, it is logical that the outcome was so high, but it may not accurately reflect the participants' true integration into the community. While the social group does allow for interaction between members and typically developed people within the community, these

people are often volunteers or are paid to be at the social group. If this is the only community integration that the participants experience in their lives, these results should be interpreted with caution.

Further, the post-test interview also found that four participants reported that people outside of their home almost never ask them for help or advice of any kind. This implies little interaction between the participants and people in the community. It may also suggest that the individuals with developmental disabilities might not have the confidence to give advice, or it might mean that people do not see individuals with disabilities as someone from whom to seek advice. This is perhaps not surprising given the previously discussed stigma and the negative attitudes towards individuals with developmental disabilities (Foley et al. 2014; Foley and Chowdhury 2007; Overmars-Marx et al. 2014; Schalock 1990). For the betterment of individuals with disabilities and all members of society, it is important that we advocate for changes that help these individuals gain a greater sense of confidence in their capabilities. Further, it is also important that typically developed individuals recognize the capabilities of people with developmental disabilities and encourage their participation in the life of the community. Much like Scior (2011) proposed, public attitude must change in order for social inclusion to occur for this population. More research is needed regarding community integration for people with developmental disabilities because integration potentially allows this population to expand their social networks and increase social role opportunities.

*Friendships.* Another common theme that arose in the qualitative data was friendships. When asked about their friends, all participants said that having friends was important; five participants indicated that they wanted more friends; five said they did not see their friends enough, and five reported that they wanted more intimate relationships with people they can

confide in. Further, the LSS revealed that two of the participants want to live in a different home in order to make more friends; specifically, one wants to move to a community integrated living arrangement (CILA), or an apartment sponsored by the nonprofit. The other wishes to move out of state to live with his sibling. For four participants, the other social group members were the only friends they reported having. Additionally, all participants reported that the social group was the place where they saw their friends the most, suggesting that they are restricted to a scheduled time frame to see their friends each week with very little flexibility in this schedule. The lack of schedule flexibility supports previous research in that communication with friends is limited (Mithen et al. 2015). Additionally, this finding might also imply a lack of access to transportation (Schalock 1990; Schalock et al. 2000) because the participants may not have the transportation resources necessary to see their friends outside of the scheduled social group. This is important to note because this lack of freedom to interact with friends outside of structured activities may prevent the participants from increasing their social networks (Mithen et al. 2015).

*Living Arrangements.* Living arrangements were another theme in which many participants shared a common desire. Overall, participants indicated that they have positive experiences in regards to their living situation. Interestingly, of the many potential living arrangements, such as group home living, independent living, and living with a family member, all of the participants live in a house with either their parents or another family member. The participants reported that they liked where and with whom they lived, enjoyed the food, and liked their neighborhoods. Though all gave a positive response that indicated they liked where they lived, some participants also indicated the desire to live somewhere else.

It is important that we address these desires because they may indicate a lower life satisfaction. Those who wish to live somewhere else might perceive a lack of freedom or independence. One participant, for example, very passionately declared that he wanted to live in a CILA. The non-profit organization sponsors a variety of CILAs throughout town, but financial assistance is needed before placement can occur. This particular participant seemed to understand the placement process as he stated, "I've been waiting patiently. I'm going to tell the government to get their act together." He mentioned the government and his desire to live on his own several times throughout the interview. It is likely that this desire underscores a lack of satisfaction in the participant's life, and he thinks that having the freedom to live on his own will make him more satisfied. This is a logical thought process given that a sense of agency and the ability to make choices regarding one's living situations has been linked to higher life satisfaction (Gardner and Carran 2005). Moreover, this freedom may lead to more role opportunities in that he would potentially be able to make more decisions regarding his daily activities or integration into the community.

Further, a second participant explained that she would be moving out of her parent's house when she turned 53 (she is currently 49). She had mixed emotions about this; she is excited to do fun activities with roommates, but she also loves living with her parents. This participant seems to be struggling with her attachment to her parents and the desire for more independence. Her excitement about spending time with roommates might suggest the desire for more social roles because she not only wants to fulfill the role of roommate and friend, but she also wants to experience the freedom and independence of going out to restaurants and integrating more into the community with her friends.

It is also important to note that three other participants wanted to move into a CILA. One stated, when explaining her relationship with her parents, “We all argue a lot. It’s not good.” She wants a more independent role in which she is able to live with a roommate and make her own decisions. The second participant wishes to try living on his own because he wants to socialize more, implying a desire for more roles or an expansion of his social network. Finally, the third participant claims that her current home is too small, and she prefers to live on her own so she has more privacy. She also asserts that she is prepared to take on new roles, such as cooking or cleaning, in order to live on her own.

In summary, while all of the participants like where they live, some participants either strongly desire to live somewhere else or are somewhat interested in the idea of living more independently. It is important that we do not mistakenly interpret the participants’ positivity about their current living arrangements as evidence that they do not wish for other opportunities. Those with other desires showcase that not all participants are completely satisfied with their living situation. Perhaps giving them a new role such as roommate may enhance their quality of life. Additionally, roles typical to that of a homeowner (i.e. cooking, cleaning) may provide participants with a greater sense of independence.

*Recreation.* Furthermore, the interviews indicated that participants desire more recreational opportunities, which yet again aligns with previous findings (CQL 2008). Five of the participants reported that they are almost always bored, with five also claiming they watch television six or more hours each day. Participants explained that they want more opportunities for activities to do in their free time such as playing sports, going to parties, playing cards, going out to eat, and going to the movies. The need for more opportunities to engage in recreational or community activities is clear, and this aligns with previous research (Forrester-Jones et al. 2006).

Participants want to be involved in more activities, but only three reported that they have the freedom to make their own decisions regarding what they do in the community. This is concerning because it showcases that the majority of participants do not make their own decisions, and therefore rely on someone else to tell them what they will and will not do. Without proper access to community activities, these individuals are perhaps deprived of the chance to accept the social roles they may want. Agency cannot be ignored because something as seemingly simple as choice can greatly impact one's quality of life (Schalock 1990; Schalock and Siperstein 1997). If the participants are given more freedom to choose the activities they wish to do in the community, they may then have more access to social role opportunities. It is crucial that people advocate for more independence for the developmental disability community, especially since they want to participate more in the life of the community (CQL 2007; 2008).

## DISCUSSION AND CONCLUSION

Quality of life did not significantly increase for the participants who received the new social role opportunity of snack preparation during our six-week intervention; therefore my hypothesis was not supported. It is important to note that this finding is difficult to evaluate in the context of existing literature because we were not able to identify any experimental studies aimed to improve quality of life via new social role opportunities. Additionally, although the data from the social capital index suggests that the participants have more social capital than the comparison group, we cannot definitively claim that this is the case due to the small sample sizes of both the participants and the comparison group. Thus, the hypothesis that the social group members would have more social capital needs further investigation.

Qualitative analysis reveals that the participants share a common desire for more social roles. This is not surprising given that previous literature has found this as well (Bigelow et al.

1982; CQL 2007; Gardner and Carran 2005; Forrester-Jones et al. 2006; Schalock 1990). Similar to Mithen and colleagues' (2015) findings, participants indicated that they were unable to see their friends enough. A lack of opportunities to communicate with friends or other members of the community is a common finding when working with this population (CQL 2007; Mithen et al. 2015; Schalock 1990; Schalock et al. 2000), suggesting that more research still needs to be done in order to determine ways to enhance communication, and in turn increase social role opportunities. The perceived lack of social roles that the participants reported might suggest that their quality of life is lacking (Forrester-Jones et al. 2006; Gardner and Carran 2005; Schalock 1990). While the results of this study do not lead to a significant finding, the results do provide support for previous research as well as re-emphasize the need for more research.

### *Limitations*

There are some limitations to this study that must be addressed. First, the sample size is small, and as a result, it might not accurately represent the larger population of individuals with developmental disabilities. The fact that, coincidentally, all of our participants lived at home with family may have somehow influenced our findings as well. A larger and more diverse sample is needed in order to determine whether new social role opportunities influence quality of life. Second, the length of the intervention was quite short. Six weeks may not be enough time to truly establish the presence of a new social role, especially given that the intervention took place only once a week. A third limitation of the present study is that we did not include individuals who could not communicate verbally. Despite our decision to exclude these individuals, it is crucial that research be done to determine quality of life for individuals who are unable to communicate verbally as well. Finally, the measures used in this study are slightly dated, except for the San Martin Scale.

Despite the limitations, this study still provides important insight into the lack of social role opportunities for individuals with developmental disabilities. Though the sample size is small, I was still able to get a glimpse into the lives of our participants and determine how they perceive the quality of their lives. I learned that while the participants indicate they are happy in many regards, there is still a common desire for more roles, whether in the community or in regards to independent living. The intervention only lasted for six weeks, and did not result in statistically significant findings, yet the snack making activity did impact the experimental group's lives, if only in a small way. As described before, participants of the experimental group were eager to assist me each week, repeatedly expressed that they liked making the snacks, and would talk to me about the activity without my coaxing. Despite the lack of statistically significant findings, many participants appeared happy to be involved in the snack preparation and showed excitement while helping out.

Though we excluded individuals who could not communicate verbally from participating in the study, all members of the social group were given the snacks and were included in all other areas of the social group. As previously mentioned, the decision to avoid the use of proxies, except in the case of the staff-report questionnaire, was influenced by past literature in the field (Cummins 1997), and was my attempt at obtaining a true self-report; by investigating how the participants perceive their own lives from their point of view. The measures, excluding the San Martin Scale (Verdugo et al. 2014b), are slightly dated, but this highlights a great need for modern measures to evaluate quality of life for this population. Obtaining measures and manuals was challenging, and this is concerning because it may illuminate a serious gap in the field. If the appropriate measures are not designed, then how do we properly assess quality of life? Perhaps one factor that contributes to the lack of social role opportunities is that researchers



and social service organizations do not have the resources and tools to appropriately evaluate these opportunities, or lack thereof. If the self-report measures for quality of life are cumbersome to use, difficult to obtain, and/or challenging to score, it is unlikely agencies and researchers will rely on the perceptions and reports of the individuals themselves. This is challenging when trying to obtain an accurate report of one's life. I chose the measures because they have been cited in previous literature, provided acceptable psychometrics, and because there were few alternative choices when looking for self-report questionnaires and interviews.

### *Future Research*

The present study served as a pilot study; in addition to examining the effects of a new social role, it was also meant to begin the discussion on how social role opportunities may influence quality of life for individuals with developmental disabilities. Future research should include a larger sample size. I recommend reaching out to various organizations, residential homes, and so forth to enhance the potential number of participants. A larger sample may help account for subsequent attrition, as well as allow for parametric analyses. Unfortunately, however, recruiting a large sample size for this population may remain a challenge. An alternative research design might be to utilize a matched groups design. A matched groups design would match the experimental and control groups on one or two factors such as verbal ability, age, or gender, for example. This design would allow the researcher to better control for individual differences.

Additionally, future research should include a longer and more robust intervention. This study focuses on a minor role (i.e., snack preparation), but future studies could expand upon this and create more role opportunities that focus on larger role opportunities (e.g., taking care of a garden, organizing a social event, etc.). Moreover, instead of one weekly activity, the

participants in the experimental group could begin leading several different activities (if at a social group), or take on more than one role. The intervention could potentially take place for six months in order to better develop a sense of a new social role. Additionally, future research might allow for more choice in regards to which role(s) to perform. For example, the participants might be given three or four options for possible roles they could perform, and the participants could choose a role to perform. This way, they may feel a greater sense of agency, which could potentially help increase their quality of life (Schalock 1990; Schalock and Siperstein 1997).

Another suggestion for future research would be to assess how the participants liked the role opportunity. Perhaps, by providing a brief measure immediately after the role is performed to determine how the participants feel about the activity, researchers can better understand what influence the activity has on the participants. This could also potentially help control for external factors that may influence quality of life assessment.

Possibly the most important recommendation for future research, however, is the creation of new measures to assess quality of life for this population that do not rely on proxy informants. Quality of life is a challenging construct to measure due to its subjective nature, and instruments designed to assess quality of life for this population are challenging to obtain. Without the proper measures, progress will be difficult to achieve.

Though limited, this study provides additional knowledge on the lack of social role opportunities for individuals with developmental disabilities and can serve as a helpful comparison for future experimental work with social roles. By increasing opportunities and expanding social networks, it is possible that these individuals can better meet societal expectations and increase their quality of life (Forrester-Jones et al. 2006; Halpern 2005). Addressing the lack of opportunity and increasing quality of life for individuals with

developmental disabilities is crucial because all people, regardless of ability, deserve the chance to achieve their highest potential quality of life.

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Appendix. Tables.

**Table 1. Attendance of Experimental Group Throughout Six Week Intervention**

ID	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
101	P	P	P	P	P	P
103	P	P	P	P	P	P
106	P	D	D	D	D	D
108	P	P	P	P	P	P
111	P	P	A	A	A	A
112	P	A	P	P	P	P

*Note.* P indicates present attendance. A indicates absent attendance. D indicates present attendance but declined participation. Due to participants 106 and 111s' lack of attendance, their data is not used in analysis.

**Table 2. Comparison of Social Capital Index Scores Between this Study and the Comparison Data (In percentages).**

	Present Study (n=11)	Comparison Data (n=9)
Social Capital Index	72	51
Bonding Social Capital	75	57
Bridging Social Capital	67	41

*Note.* This data should be interpreted with caution given the small sample sizes. Although the data from the present study suggests that membership in a social group produces more social capital, we cannot make this claim given the small sample. Data is given in percentages.