# THE USE OF SOCIAL NETWORK ANALYSIS TO ASSESS SOCIAL SUPPORT AMONG YOUNG ADULTS WHO EXPERIENCE DISABILITY: A PROGRAM EVALUATION

A Dissertation

by

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# ABSTRACT

Intellectual and developmental disabilities (IDD) impact individuals across all racial, ethnic, and socioeconomic groups and those who experience IDD have higher rates of loneliness and social isolation. Through supportive relationships, individuals with disabilities can mitigate the negative health outcomes related to loneliness and isolation (i.e., abuse, exploitation, mental health disorders, lower quality of life). Social network analysis (SNA) is a theory and methodology that allows researchers to understand the connections between people and observe the adoption, spread of beliefs and behaviors, and impacts relationships have on an individual. The purpose of this dissertation was to use SNA to investigate the perception of social support among individuals with intellectual and developmental disabilities (IDD). To do so, we conducted a scoping literature review and two SNAs.

The scoping review documented 7 studies investigating the social networks of individuals with IDD. This review provided insight into how studies have been conducted and network composition of those with IDD. The first SNA comprised an egocentric network analysis and measured the characteristics related to social support within a sample of individual with IDD who attend a career preparation program. The second SNA utilized a sociometric network design to measure network characteristics related to depression within the same sample.

Results from a scoping review and two SNAs suggest: (a) SNA is an applicable method to assess social support for individuals who experience IDD; (b) multiple name generators are a promising tool to differentiate types of social support; (c) the social networks of those who experience IDD have the ability to grow if given the opportunity; and (d) individuals with IDD can provide support to each other. Implications for future research and practice are discussed.

# DEDICATION

This dissertation is dedicated to Dr. Kenneth McLeroy. Thank you for challenging my thinking and imploring me to think beyond the individual. Your wisdom will be greatly missed.

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# NOMENCLATURE

| | |
|---|---|
| IDD | Intellectual and Developmental Disabilities |
| PATHS | Postsecondary Access and Training in Human Services |
| QAP | Quadratic Assignment Procedure |
| MR-QAP | Multiple Regression- Quadratic Assignment Procedure |
| SNA | Social Network Analysis |
| PHQ | Personal Health Questionnaire |
| PSE | Postsecondary Education |
| PRISMA | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |

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# CHAPTER I

# INTRODUCTION

## Introduction

Historically, those with IDD were institutionalized and deemed as “other,” thus being removed from society (Johnson & Traustadóttir, 2005). In the last several decades, deinstitutionalization has occurred; however, people who were in the IDD community have not felt a sense of belonging or meaningful relationships when physically included in society (Lippold & Burns, 2009; Myers et al., 1998). Meaningful relationships with others are essential for all people, but especially for individuals with IDD. Through connections to others, individuals can obtain social capital and better their quality of life (Myers et al., 1998; Stancliffe et al., 2007). Thus, the purpose of this dissertation is to explore the social connections among individuals with IDD. By conducting a scoping review, and egocentric network analysis, and a sociometric network analysis, we will answer the following research questions: 1) in what ways has social support been measured and studied in youth and young adults experiencing IDD, 2) what are the composition of specific types of social support within egocentric networks for individuals experiencing IDD, and 3) to what extent are the relationships and dynamics within whole networks created and fostered within the PATHS program?

A 2011 meta-analysis found the prevalence of individuals experiencing intellectual and developmental disabilities (IDD) across the life span to be 10.37/1000 or 1.04% of the population (Maulik et al., 2011). A follow-up systematic review concluded that the prevalence ranged from .05 to 1.55% (McKenzie et al., 2016). Most prevalence estimates are based on parent or guardian reports of ever receiving a diagnosis of an IDD from a doctor or other health care professional (Zablotsky et al., 2017). A study by the U.S. Census Bureau determined around 1.2 million civilians, non-institutionalized adults experienced disabilities in 2010, and the male to female ratio is 10 to 7 (Brault, 2012; Maulik et al., 2011). Disabilities occur among all racial, ethnic, and socioeconomic groups.

## Social Capital

Social capital has many different definitions and conceptualizations; however, originally, it was identified as goodwill, fellowship, mutual sympathy, and social interaction among a group of individuals and families who make up a social unit (Hanifan, 1916). It was later expanded to other disciplines, though foundationally, maintains the concept that participation in groups can produce positive outcomes and experiences for individuals. Coleman claims that people are "shaped, redirected, and constrained by the social context" in which they live (Coleman, 1988, p. S96). Social capital activation and attainment occurs through interaction within social relationships. Through the examination of different types of relationships and aspects like their structure and function, resources and support can be better understood.

Social capital can be broken into three types of relationships: bonding, bridging, and linking relationships (Gittell & Vidal, 1998; Putnam, 2000; Szreter, 2004). Bonding relationships typically are created with people who share similar attributes, or people who are homophilic (Lin, 2002), and these relationships provide emotional support because of shared experiences (Warschauer, 2004). The more similar people are, the stronger the connection, but these relationships usually do not provide added value in terms of resources or “getting ahead” (Lin, 2002; McPherson et al., 2001). For example, a teenage relationship with a peer who is a similar age, race, and socioeconomic status can create an instantaneous bond (e.g., emotionally, sense of belonging); however, this friend most likely does not have the ability to help financially or have connections for a better job. Alternatively, bridging relationships provide access to resources outside of bonding relationships and are typically formed between dissimilar individuals (Lin, 2002). Because those who are similar typically have and use similar resources, these connections to less hemophilic people (e.g., people in different life stages or from different geographic locations) offer opportunities to access new and different resources. Finally, linking social capital is the extent to which relationships are built with those who have power, either institutions or individuals. Linking relationships are characteristically weaker ties but through them, individuals can have access to services and resources (Granovetter, 1973; Lukasiewicz et al., 2019). Ultimately, social capital represents resources obtained, either directly or indirectly, through a social network. Social support is a subset of social capital, where social capital includes the societal norms and the networks utilized to obtain resources, and social support focuses on the perceived relationships and types of support provided (Khazaeian et al., 2017).

## Social Support

Connections to other people and support provided by them can provide a multitude of benefits, including lowering rates of depression, stress, and anxiety (Cohen, 2004; Kawachi, 2006). Those with high quality or quantities of social connections have a lower risk of mortality, even when health status (e.g., preexisting conditions) is controlled (Berkman et al., 2000). Additionally, social isolation can be linked back to all cases of mortality (House et al., 1988). For those with IDD, relationships can be difficult to obtain and maintain. People who experience disability have higher rates of loneliness and social isolation than their neurotypical peers (Margalit, 2004; Sheppard-Jones et al., 2005). Further, loneliness and isolation are risk factors for abuse, exploitation, mental health disorders, and lower quality of life (Stancliffe et al., 2007). Given these health implications, is it important to ease loneliness and increase the quality and quantity of social support, particularly for those with IDD (House et al., 1988; Stancliffe et al., 2007).

There are many types of social support, but three types are instrumental for the success of young people with disabilities, including: 1) belonging support, 2) appraisal support, and 3) tangible support. Belonging support creates a sense of social inclusion and that others are there for a person (Glanz et al., 2008; Kent de Grey et al., 2018). A sense of belonging can aid in the perception of wellness and relieve symptoms indicating illness because a sense of attachment to others can have a calming effect (Hale et al., 2005), decrease depression (Hagerty & Williams, 1999), and mitigate risk- behaviors (McNeely & Falci, 2004). Because individuals with IDD have a difficult time integrating into society and feeling accepted, the reinforcement of belonging support can have impact on mental health (Civitci, 2015; Hagerty & Williams, 1999). Appraisal support, sometimes called informational support, is the supplying of information, advice, or suggestions (House et al., 1988). For example, one might find appraisal support in a mentor who can give life or job advice. The ability to access this type of support equates to better health outcomes (Uchino, 2006), better life decisions (Niles, 1996), and adjustment (Malecki & Demaray, 2003). Individuals with IDD face challenges daily adjusting to their environment and some are presented with opportunities to explore independence. Access to appraisal support can help assist people with IDD in making better decisions, resulting in positive health outcomes. Lastly, tangible support is the provision of physical, financial, or material assistance (e.g., labor, goods; Kent de Grey et al., 2018). Though similar to appraisal support, tangible support is more focused on physical provisions as compared to verbal or informational advice. Tangible support is associated with better physical functioning (Woloshin et al., 1997), psychological well-being (Coffman, 2008; Friedman & King, 1994), and stress (Krause, 1986). Those with IDD tend to not have tangible resources of their own (Perkins & Haley, 2013) and thus, have to acquire such capital from their social networks, making this support all the more necessary for those with IDD.

## Social Network Analysis

The social interactions and the provision of support can be theorized using social network analysis (SNA). According to network theory, the structure of a particular group distinctively influences a singular component within the group (e.g., person, species, organization, cell, neuron), and certain positions can have unique influences on people within a network (Freeman, 1979; Hinde, 1976). In social science, network theory posits that network structure facilitates the adoption and spread of behaviors across the group

(Alexander et al., 2001; Rogers & Kincaid, 1981; Valente et al., 2005). Additionally, the theory hypothesizes that persons who belong to the same groups (i.e., cliques) often exhibit similar behaviors and characteristics (McPherson et al., 2001; Valente, 2010).

Social network analysis is also a set of tools that can be used to quantify the influence of relationships and social processes on behavior and health (Wasserman & Faust, 1994). At the foundation, SNA in health research assesses the relationships between a single entity (e.g., individual, community, organization) and the context in which they exist, instead of focusing on the individuals themselves (Valente, 2010). There are two different approaches to SNA. One approach is whole network analysis, or sociometric analysis, where an entire group of people (nodes) are examined to observe how parts of the network and structure influence an outcome of interest (Borgatti et al., 2013). In sociometric analysis, all individuals within a bounded group are studied and asked about the interactions solely within that group (Perry et al., 2018; Valente, 2010). All respondents provide their ties to others but also have the potential to be a contact provided by another individual. Data is analyzed to understand the impact of structure and patterns across the bounded network. The other approach is egocentric network analysis. This approach places an individual (ego) at the center of the analysis and attempts to understand how their local, perceived network (alters) influences behavior (Perry et al., 2018). Name generators are utilized to produce nominations of other individuals (alters) and information is collected about alters using name interpreters. Data is examined to infer the impact of network composition, individual characteristics (homophily and heterogeneity), and structure between alters (alter-alter ties) on an outcome of interest. In egocentric data analysis, alters will vary from ego to ego since they are not being nominated from a specified group and can be randomly sampled; whereas, in sociometric analysis requires census-style data collection of the entire group.

Though some studies have used SNA among persons with IDD, the literature is limited. Of studies that have investigated adults with IDD via SNA, most have focused on: degree of social integration (Carter & Hughes, 2005; Hughes et al., 1998; McGaughey et al., 1995; Rossetti, 2011); friendship and loneliness (Hill & Dunbar, 2003; Robertson et al., 2001; Stancliffe et al., 2007; Verdonschot et al., 2009); factors that are associated with social inclusion (Perry & Felce, 2005; Robertson et al., 2001; Stancliffe et al., 2000); and interventions to increase social inclusion (Amado et al., 2013; Hayden & Abery, 1994; Hughes et al., 1998; Smith, 2007). However, this research is missing a vital component of the relationships: the social setting in which they occur. Most research focuses on the types of relationships (i.e., parents, support staff, friend) without more deeply examining the properties of relationships (e.g., value placed on relationship, specific support provided). Through a diverse lens, better understanding of the unique interactions through the exchanging of different types of support between and among network ties, plus the particular roles people play, is possible.

## Postsecondary Education and the PATHS Program

Postsecondary education (PSE) is necessary for any person hoping to gain impactful employment and live independently (Katsiyannis et al., 2009). The goal of PSE is not always to receive a degree but can be to gain college experience and functional skills. Additionally, higher education can increase happiness, self-esteem, and health outcomes (Thoma et al., 2011). PSE opportunities for individuals with IDD has increased the last thirty years (Horn & Berktold, 1999). Policy requirements like the Americans with Disabilities Act have increased standards as well (*Americans with Disabilities Act of 1990*, 1990; Brault, 2012), increasing inclusiveness and accessibility for those with IDD. Unfortunately, most IDD students who enter PSE do not stay in college or obtain a degree (Katsiyannis et al., 2009). It is important to tailor PSE programs to accommodate those with IDD to ensure success.

The Postsecondary Access and Training in Human Services, or PATHS, certificate program is a career preparation program provided through the Center on Disability and Development at Texas A&M University's College of Education and Human Development. This and other college-initiated programs differ from other PSE opportunities that are offered through local communities or schools because they teach college-level classes instead of life skills (Zhang et al., 2018). The participants are provided one semester of coursework coupled with a semester-long practicum. The programmatic goal is for participants who experience IDD to earn a certificate that combines classroom instruction with practical career-building to become a Direct Support Professional (e.g., helping others who have disabilities) or Child Care Professional (e.g., in a daycare or school; *PATHS Certificate Program*, n.d.; Zhang et al., 2018). In addition to classroom instruction, on a need basis, individuals can receive supports and trainings on academics, life skills, independent living, and peer mentoring that is provided by Texas A&M University undergraduate and masters students. The PATHS program has the opportunity to provide social support and capital to all participants and a chance for participants to provide support to each other through resource provision, education, and trusting networks. All participants are between 18-25 years old, which is considered a transitional age— indicating that individuals are losing social supports from their current educational system but also becoming independent. The PATHS program and other PSE programs could assist in creating support systems that have been lost through the educational system.

This dissertation will provide additional insight into network literature related to persons with IDD. Results of this study and potential future investigations are critical to better understand how one's social network affects health behaviors, particularly social supports for those experiencing IDD. As inclusive practices continue, and integration of those with IDD into public spaces occurs, research into networks must continue to evolve. This project will provide insight in two ways: 1) discovering if there are important people and patterns within social networks that distinctly impact social supports and quality of life for those experiencing IDD, and 2) identifying network characteristics that are tied to success within the PATHS program. Additionally, there are implications of this work as universities around the nation create on campus certificate programs for those with IDD. The research conducted during this dissertation can provide a baseline for later replication of similar studies. Through understanding the support networks of PATHS participants, other programs like PATHS can benefit from findings and use them to inform the development of or adaptations to their program. The goal of this research is to examine the nuances in relationships that provide different types of social support to persons with IDD, both bounded by the PATHS program and within an individual’s life, and to expand the use and knowledge of SNA in health behavior research.

This dissertation consists of five chapters. Chapters II, III, and IV represent manuscripts that will be submitted for publication in peer-reviewed journals. The following is a description of each chapter:

- Chapter I provides the reader with an introduction and overview of social capital, and social support for individuals with intellectual and developmental disabilities (IDD) and social network analysis, as well as the purpose and significance of the dissertation.
- Chapter II is a scoping literature review on the social networks of those with IDD, specifically regarding research methodology and network composition.
- Chapter III documents the findings of an egocentric network analysis of social support provision for a group of young adults who experience IDD.
- Chapter IV documents the findings of a sociometric analysis to understand social support within a group of young adults who experience IDD.
- Chapter V provides a brief summary of the findings from chapters II-IV. Implications for future research and practice concerning social support and social network analysis are also discussed.

# CHAPTER II

# SOCIAL NETWORKS OF INDIVIDUALS WHO EXPERIENCE INTELLECTUAL AND DEVELOPMENTAL DISORDERS: A SCOPING REVIEW

## Introduction

Intellectual and developmental disabilities (IDD) is a classification of any disorder that negatively impacts an individual's ability to typically develop (e.g., physically, intellectually, emotionally; Centers for Disease Control and Prevention, 2012). Between .05 and 1.55%, or 1.2 million people, of the United States population is diagnosed with some sort of intellectual or developmental disability (Maulik et al., 2011; McKenzie et al., 2016). These prevalence rates are estimated based on a parent or guardian reporting that a doctor or other health care professional confirmed a diagnosis of IDD. Males are disproportionally diagnosed with IDD at a rate of 10 to 7 compared to females (Brault, 2012; Maulik et al., 2011). However, disabilities occur among all racial, ethnic, and socioeconomic groups.

Research regarding people who have IDD has changed over the last several decades because the way society has accepted and treated those individuals. The United States has shifted from institutionalization to societal integration, and research has paralleled this shift going from physical inclusion to social inclusion (Myers et al., 1998). In some parts of the world, those with IDD are still deemed as "other," and do not have the chance to integrate with society (Mussida & Sciulli, 2019). In the United

States, policies like the American's with Disabilities Act have begun the shift towards equality (*Americans with Disabilities Act of 1990*, 1990).

For those with IDD, social integration and acceptance into society can be difficult (Carter & Hughes, 2005; Hughes et al., 1998; McGaughey et al., 1995; Rossetti, 2011). Compared to nondisabled adults, those with IDD typically do not have as many social relationships and the ones that are established typically contain family members and paid caregivers or support staff (Forrester-Jones et al., 2006; Krauss et al., 1992). This has been attributed to limited social skills and lower-quality relationships compared to neurotypical individuals (Cunningham et al., 2009). If a person with an IDD lives at home, their social connections are typically similar to that of their mother (Krause, 1986). Social connections are essential to thriving because through them, individuals have the opportunity to attain resources and support (Myers et al., 1998; Stancliffe et al., 2007). Thus, adults with IDD are likely missing out on resources and support often available through social networks.

## Social Capital

Social capital is an outcome of understanding the structure and function of relationships, and is defined as resources and support provided through social interactions (Lin, 2002). Social capital can be conceptualized through bonding, bridging, and linking relationships (Gittell & Vidal, 1998; Putnam, 2000; Szreter, 2004). Bonding relationships are created by people who share similar attributes (e.g., age, gender, social status). Bonding capital often creates emotional support because there are shared experiences and understanding between similar individuals (Warschauer, 2004). One example of a bonding relationship would be through two people providing emotional support and forming an attachment by having shared traumatic experiences (e.g., rape, miscarriage, abuse). Bridging capital usually develops from relationships with people dissimilar to an individual on a given characteristic or set of characteristics (e.g., age, social status, education; Lukasiewicz et al., 2019). These relationships are beneficial because they allow individuals access to resources outside of their social circles that are often not available to them or people similar to them (McPherson et al., 2001). For example, networking with peers at professional conferences from various institutions could allow for access to or knowledge of resources unknown or unavailable to an individual at their home institution. Linking social capital is the extent to which relationships are built to people and institutions who have power (Lukasiewicz et al., 2019). These relationships are typically weak but allow individuals access to structures and systems used for "getting ahead" (Lukasiewicz et al., 2019). It is through the various relationships, such as bonding, bridging, and linking relationships, accessed through social networks, that social capital is obtained.

If networks do not form, as is common for adults with IDD (Forrester-Jones et al., 2006), then individuals will have less access to activate social capital. In addition to social capital, social relationships have been tied to psychological outcomes, including increased happiness (Brim, 1974), better self-esteem (Cohen & McKay, 1984), and mental health outcomes (Clara et al., 2003; Weber et al., 2010). However, those who experience IDD have higher rates of loneliness and isolation (Margalit, 2004; Sheppard-Jones et al., 2005). Both isolation and loneliness are predictors of abuse, exploitation, mental health disorders, and lower quality of life (House et al., 1988; Stancliffe et al., 2007). Additionally, across all people groups, all cases of mortality can be traced back to social isolation (Berkman & Syme, 1979; House et al., 1988). Understanding the types of relationships that an individual's network is composed of can provide insight into the support that they receive (e.g., emotional, mental, informational, tangible resources) and outcomes they may experience. Additionally, through further comprehension of the social networks for those who experience IDD, adverse health effects could be mitigated.

## Social Network Analysis

Social network analysis (SNA) is a theoretical framework and methodology that assesses relationships between entities through the mapping of networks. These units (nodes) can be humans, cells, species, or anything that interacts. The relationships between the entities are called ties. SNA posits that through social connections individuals can receive goods and resources, but also have opportunities to be influenced (Freeman, 1979; Hinde, 1976). The structure of the network and position of the nodes can result in differing health outcomes but also indicate the influence that an individual has on the rest of the network (Valente, 2010)

Given the importance of social support made available through social networks for all people, including adults with IDD, and the contributions SNA can make to measuring and understanding networks, it is important to take a network approach in studies investigating social inclusion and support among people with IDD. Thus, this paper aims to conduct a scoping review of studies exploring the social networks of individuals with IDD. More specifically, this review will examine how networks have been assessed and conceptualized for individual with disabilities, along with understanding the composition of their networks. The goal of a scoping literature review is to map the key concepts underpinning a research area, especially when area is not extensively reviewed. A scoping review provides a mechanism to view the range of studies (i.e., extent, variety, characteristics) and discover gaps in the current literature (Arksey & O'Malley, 2005; Tricco et al., 2018).

## Methods

Arksey & O'Malley's (2005) explanation and methods of a scoping review was used as a guidance for this review. The process for their method included: 1) identify the research question, 2) identify relevant studies, 3) select studies, 4) chart the data, 5) summarize and report the results. A librarian experienced in systematic and scoping reviews for a variety of health topics designed the search. Three databases were searched between October 2019 and March 2020 (Medine, Ebsco Cinahl, and PsychINFO). A combination of search terms related to persons with disabilities and social networks were utilized. The Cochrane Collaboration standards of search strategy structure was utilized (i.e., searching in keyword, thesaurus, title, and abstract fields; Higgins et al., 2019). *Table 1* provides the search terms and search order for the online Medline database.

### Selection

After conducting key word searches, citations were then uploaded into Covidence, an online software to manage literature reviews (*Covidence Systematic Review Software*, n.d.), to be sorted based on titles and abstracts. Deduplication occurred during this time as well. To be eligible for inclusion, studies had to focus on the social networks of people who have intellectual and developmental disabilities. Inclusion criteria included articles that assessed the networks of individuals who had disabilities, took place in the United States, and collected data directly from the individuals (as opposed to collecting data from a parent or guardian). Articles were excluded if they were written in a language other than English, not peer reviewed, occurred outside of the United States, and did not collect data directly from those with disabilities (i.e., parents, caregivers). Studies that took place outside of the United States were excluded because social norms differ across counties when it comes to social integration and acceptance into society for those who experience disabilities (Mussida & Sciulli, 2019). Only studies that collected data directly from individuals who experience disabilities were included because the research indicates that the perception of support impacts health, not necessarily the activation of support structures (Wethington & Kessler, 1986). In order to assess perceptions, individuals must provide the data. There was no exclusion on date published. One reviewer read all titles and abstracts to find the relevant articles for full text review.

## Coding

Relevant data from the studies were extracted using a Google Form and exported to a matrix. The form was designed to gather information about study design, participants, data collection, and outcomes. One reviewer assessed all articles.

# Results

In total, 408 articles published between 1982 and 2020 were identified through the database search. Four of those articles were removed because they were duplications. Of the original 408, 321 were excluded at the title and abstract level. Eighty-three articles were included in the full text review. Seventy-six articles were ultimately removed and seven full-text articles were reviewed. Articles were excluded because a) they took place internationally (n=53), b) individuals were not the sources of data (n=8), c) they were not a research study (i.e., commentary; [n=4]), or d) networks were not included (n=4). The PRISMA flowchart can be found in *Figure 1* (Tricco et al., 2018). See *Tables 3* and *4* for the full matrix.

## Sample Characteristics and Study Designs

**Sample characteristics**. Of the studies reviewed in this paper, over half (57%) studied children (Coleman & Minnett, 1993; Cosbey et al., 2010; Cunningham et al., 2009; Hoyle & Serafica, 1988); while one studied young adults transitioning out of high school into adulthood (Barone et al., 1993) and two focused on adults (Ouellette et al., 1994; Ward et al., 2013). Sample sizes ranged from five to 61 people with disabilities, though 71% of studies had comparison groups of neurotypical participants so their overall sample size was higher (Barone et al., 1993; Coleman & Minnett, 1993; Cosbey et al., 2010; Cunningham et al., 2009; Hoyle & Serafica, 1988). Across most studies, except for Ouellette and colleagues (1994), a majority of males made up their sample of individuals with disabilities. Four of the studies took place in the school system (Barone et al., 1993; Coleman & Minnett, 1993; Cosbey et al., 2010; Hoyle & Serafica, 1988), while the remaining three took place in the community, a long-term housing facility, and within an educational program. *Table 2* provides further insight into the sample characteristics. See *Table 3* for all network measures and outcomes of the literature review.

**Study designs**. Studies published in the literature used mostly a cross-sectional study design (57%). Two studies had a pretest/posttest design (43%) and one was longitudinal, or a time series design, with data collection before the intervention, at the end of the intervention, and 10-week post. There were no randomized control trials reported, and no qualitative studies met inclusion and exclusion criteria for this review.

## Network Components

**Name generators.** In order to collect data from individuals, some sort of question was asked to elicit names of people within one's social network. In the social network literature, this is called a name generator (Borgatti et al., 2013; Valente, 2010; Wasserman & Faust, 1994). Four of the studies used previously created measurement tools: Analysis of Social Support in School Transitions (ASSIST; Barone et al., 1993), CAPE scale (Cosbey et al., 2010), Social Network Inventory for Children (Cunningham et al., 2009), and Social Network Analysis Form (SNAF; Ouellette et al., 1994). Two of the studies used a blanket statement and had participants name those in their network until they could not name anyone else (Hoyle & Serafica, 1988; Ward et al., 2013). Those questions were "who are the people you know best" and "who would you do something fun with." For their name generator, Coleman and Minnett (1993) provided students with a roster of all other students in their class, who were the same gender as them, and had students denote three classmates they like to play with, three classmates they like, and three classmates they dislike.

**Ties.** Social ties can serve a multitude of purposes and authors can tailor the nominations to fit their research questions (Perry et al., 2018). All studies collected data on friendship ties. Three of the studies only assessed ties from friends or peers and not others in an individual's social network (Coleman & Minnett, 1993; Cosbey et al., 2010; Cunningham et al., 2009). Three studies also included information about parents or other familial relationships (Barone et al., 1993; Hoyle & Serafica, 1988; Ouellette et al., 1994). Ouellette, Homer, and Newton (1994) assessed relationships that were formally created—or the person is paid to support an individual (i.e., caregiver, doctor); while Ward and colleagues (2013) collected information on potential romantic relationships because they were evaluating a friendship and dating program. Non-familial and non-formal adults were assessed in the two programs that took place in the school systems.

## Outcomes

**Variables.** A variety of dependent variables were assessed across the seven studies, though they all centered around social interactions and functioning. Four studies had similar outcomes of interest. Coleman and Minnett (1993) assessed social competence or the ability to handle social interactions and maintain relationships. Cunningham and Warschausky (2009) measured social functioning, or the ability to form relationships and adjust socially; whereas Ouellette, Homer, and Newton (1994) evaluated social integration and how inclusion in activities increased network size. Cosbey, Johnston, and Dunn (2010) observed social participation amongst students with social processing disorder and their friends, attempting to understand if disabilities impact peer relationships.

The other three studies are more specific to their population and setting. Hoyle and Serafica (1988) wanted to observe how social status of students was impacted by disabilities, specifically within the school system. Ward and colleagues (2013) were evaluating a friendship and dating program and explored the relationships between participants as it pertained to acceptability and efficacy of the program. Lastly, Barone et al. (1993) appraised the social resources used to seek employment and transition after high school. Their study was focused on the social support for social capital.

**Findings.** Results were mixed concerning composition of social networks for those who have disabilities, when compared to their peers, and how they change over time. One study found that networks became smaller over time and geographic changes (Barone et al., 1993); while another found the complete opposite and that they stay similar in size. Both Hoyle and Serafica (1988) and Cunningham and Warschausky (2009) assessed the networks of children; however, one found that their networks were smaller than that of their peers, and the other found there was no difference in network size. One consistent finding came from the two adult studies (Ouellette et al., 1994; Ward et al., 2013). They found that through activities and bringing people into the same geographic space, network size can increase over time.

## Discussion

The social networks of individuals with disabilities is an under studied phenomenon. By assessing the networks of individuals with disabilities, we can infer the capital they receive and better understand how individual attributes impact the types of relationships that form. In order to fulfill the literature research aim posed originally, we conducted a scoping review of the social network research literature pertaining to those who experience disabilities and to better understand how networks were measured and the network composition of those who experience IDD.

### Study Methods and Measurement

Across all studies, there is variety in the collection and measurement of social networks. The discrepancy provides both a negative and positive impact on network and IDD literature. No two studies analyzed were alike, meaning replication has not occurred, and thus consensus on findings is not possible. The question that elicited nominations, or the name generator, were not the same across any study either. Differences in collecting names is why there are differences in outcomes (e.g., network size, impacts of time, network composition). However, this finding is a result of how social network analysis studies are designed. All networks are unique and the wording used to collect data matters, as does context of the relationship (Valente, 2010). Considering the research question, and thus how the network was generated, is critical in the interpretation of findings and the ability (or inability) to compare across studies (Perry et al., 2018). Most research focuses on the types of relationships (i.e., parents, support staff, friend) without delving into the properties of the dyads (e.g., value placed on relationship) and understanding what makes the tie, nominator, and the relationship between them unique.

The networks of adults vary from children and networks that are assessed with program or activity creation differ compared to those who are transitioning out of a supportive environment. An example of this is in the inconsistency in findings within changes in network size and composition. For students transitioning out of high school and seeking employment, their networks became smaller over time; whereas students in a 20-week program increased their network size and maintained that growth even after a 10-week break. A similar disagreement comes between the type of relationships comprising a network. For those who live in care facilities, their networks are mainly made up of formal, paid relationships (Ouellette et al., 1994) and children who live at home and still are in school have networks consisting of family members that are not as diverse (Cosbey et al., 2010).

### Network Composition

Overall, the understanding of social networks and social capital for children is limited (Leonard, 2005). Previous cognitive development literature indicates that children with intellectual and developmental disabilities (IDD) do not create as deep or meaningful friendships with their peers compared to neurotypical children (Cunningham et al., 2009; Margalit, 2004; Sheppard-Jones et al., 2005). They also experience isolation and loneliness at higher rates, which is tied to mental health disorders and decreased quality of life (Stancliffe et al., 2007). The findings from this review echo previous literature in other fields; however, Coleman and Minnett (1993), found that it might be the social status, not disability status, that impacts peer networks for children. However, disability could be the predecessor to social status, based on our understanding of stigma and disabilities (Ysasi et al., 2018). Because networks established in childhood continue throughout the lifespan (Forrester-Jones et al., 2006), if a child does not have an established network of peers and instead turns to family members and formal relationships to fulfill needs like belongingness or appraisal, then that will be the networks that follow them into adulthood.

## Network Outcomes

Ward and colleagues (2013) along with Ouellette, Homer, and Newton (1994) provided justification that when provided activities or a program, social networks have the opportunity to grow and that peers, specifically others with disabilities, can be added to a network. Additionally, those relationships did not decrease overtime when the program was over and people go home. Typically, those with IDD do not have the opportunity to increase or expand their social networks (Forrester-Jones et al., 2006). Through opportunities for exposure to others that could join an individual's network, they also have the chance to receive capital and grow. Further understanding of the dose response of these opportunities along with attributes of those that individuals create ties with is necessary.

## Study Limitations and Recommendations for Future Research and Practice

The first study limitation is that there was a narrow amount of studies that fit within the inclusion criteria, specifically studies occurring in the United States. The majority of research in this area does not take place in the US. Fifty-three articles were removed at the full-article review stage because they occurred internationally. Though they were removed because of differences in social norms and social integration abroad, important and meaningful data could have been missed. The United States has passed policies, like the Americans with Disabilities Act of 1990 and the section 504 of the Rehabilitation Act of 1973 (*Americans with Disabilities Act of 1990*, 1990; United States. Department of Health, 1978, p. 504), that have changed the way people with disabilities are treated and function in society. These policies create unique environments within their countries. Future literature reviews into social networks of those with IDD should include both domestic and international studies to see if there are observable differences between countries.

Because this was a scoping review, methodological quality or research bias was not assessed. We were interested in understanding the research that was out there and how it differed, not necessarily assess findings and come to conclusions. In a systematic review, methodology is typically evaluated in order to understand how biased the findings are or if they can be trusted (Higgins et al., 2019). In order for this to occur, future studies would need to replicate current studies so that there is more consistency between studies—whether it is the population that is used (i.e., age, setting) or methodology (i.e., name generator, design). Future systematic reviews could incorporate an evaluation of research quality and biases across studies.

More understanding of when and how network ties form is essential for the thriving and success of any people, but particularly those with IDD. These studies further cement the knowledge that those with IDD have smaller networks, less peer and more familial ties, and formal structures play a role in networks. The review does shed light onto the fact that early intervention and establishment of peer networks could impact networks into adulthood. In order for this to occur, the opportunity for people to come together and interact is needed.

## Conclusion

Findings from seven published literature articles regarding the social networks for individuals with IDD vary based on study methodology and composition of networks. The variability can be attributed to the observation of different subgroups within the IDD population (e.g., age, diagnosis) and setting. An additional finding is that networks can grow in size if people with IDD hare provided intentional activities or programs. Further investigation using SNA with this group of people is needed.

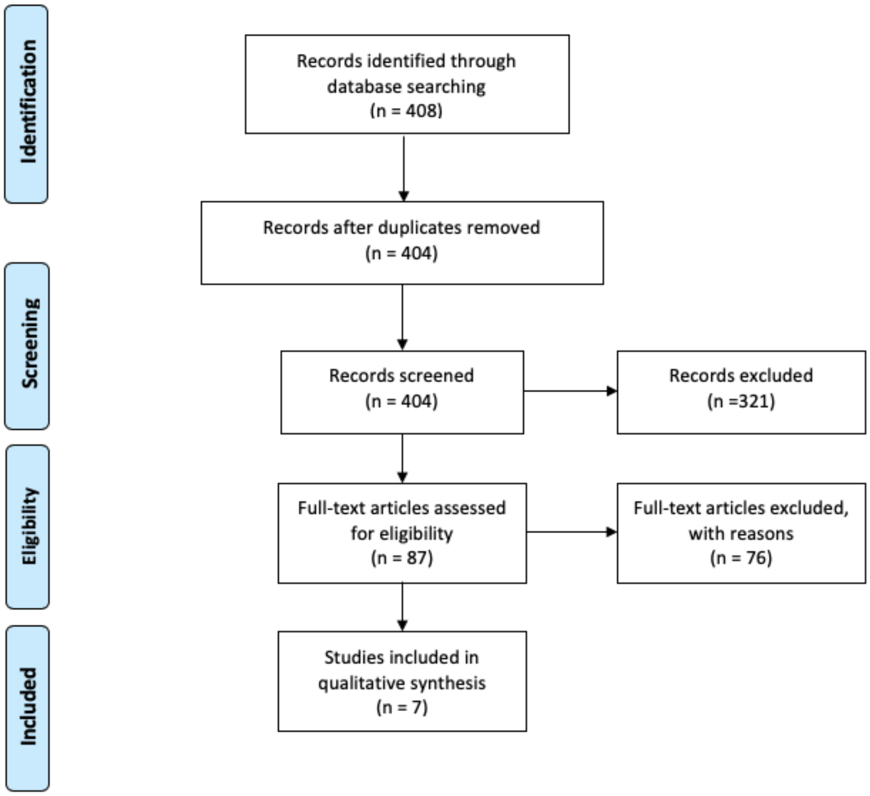


*Figure 1*. PRISMA flowchart for scoping review of the social networks for individuals with intellectual and developmental disabilities

*Table 1.* Medline search details

| Search Order | Search Term |
|---|---|
| 1. | exp Social Networking/ |
| 2. | (social adj1 network*).ti,ab. |
| 3. | (network adj1 analys*).ti,ab. |
| 4. | or/1-3 |
| 5. | exp Intellectual Disability/ |
| 6. | exp Developmental Disabilities/ |
| 7. | ((intellectual or development*) adj1 disabilit*).ti,ab. |
| 8. | or/5-7 |
| 9. | 4 and 8 |

*Table 2.* Literature review study methodology, samples, and other demographic data

| Author and Year | Setting | Age specifications | Sample size | Males | Females | Race specific | Diagnosis | Study type | Data collection method |
|---|---|---|---|---|---|---|---|---|---|
| **Barone, Trickett, Schmid, Leone (1993)** | School | Transitioning, From high school to 6months post | 234; 59 were in special education classrooms (SPED) | 35 | 24 | All | Learning disabilities (LD) and/or behavioral and emotional problems | pre/post, spring senior year and 6 months post | interviews, survey |
| **Coleman & Minnett (1993)** | School | Children/youth | 146; 61 with disabilities | 27 | 14 | All | Learning disabilities | cross sectional | survey, records, academic data |
| **Cosbey, Johnston, Dunn (2010)** | School | Children/youth | 24; 12 with sensory processing disorder, 12 matched | 11 | 1 | All | Sensory Processing Disorder | cross sectional | interviews |
| **Cunningham & Warschausky (2009)** | Community | Children/youth | 101; 41 had cerebral palsy | 27 | 14 | All | Cerebral palsy | cross sectional | interviews |
| **Hoyle & Serafica (1988)** | School | Children/youth | 187; learning disability of 23 males, non-LD of 23 for matching, non-LD classmates of 141 boys and girls | 23 | 0 | White | Learning disabilities | cross sectional | interviews, survey |
| **Ouellette, Horner, Newton (1994)** | Facility | Adults, 20-39 | 5 | 2 | 3 | All | Unknown | pre/post | interviews |
| **Ward, Arkinson, Smith, Windsor (2013)** | Program | Adults | 31 | 17 | 14 | All | General intellectual, Developmental delay | pre/post, and 10 weeks post | interviews |

*Table 3*. Network measures and outcomes of literature review

| Author and Year | Network survey or name generator | Types of tests run | Types of ties that were assessed | Dependent variable | Average number of ties | Outcomes linked to ties | Comparison group | Other |
|---|---|---|---|---|---|---|---|---|
| **Barone, Trickett, Schmid, Leone (1993)** | Analysis of Social Support in School Transitions; nominated people in their life within non-family adults, family, and peers | Descriptives, Chi-square, T-test, | Parental/familial, formal/informal, Friend, teachers, "non-family" adults | Employment, transition out of school, resources to seek employment | Assessed family, peers and non-family adults<br><u>Those with IDD</u><br>Pre: M=5.23, 3.70, 2.67<br>Post: M= 4.90, 2.93, 1.76<br><u>Mainstream</u><br>Pre: M=4.46, 3.73, 2.72<br>Post: M= 3.84, 3.17, 1.91 | People with IDD have networks comprised of family members,<br>Informal rather than formal structures were used most frequently and are perceived as most helpful in seeking and finding employment;<br>Networks became smaller with time and geographic changes | Yes; mainstream classroom | More white students in SPED than black |
| **Coleman & Minnett (1993)** | Given a roster of classmates and nominated who they play with, who they liked, disliked (limited to 3 within same gender) | Descriptives, MANOVA | Friend/ peer | Social competence | n/a | Social status impacted peer network more than disability, as did loneliness | Yes; neurotypical peers | |
| **Cosbey, Johnston, Dunn (2010)** | CAPE scale; based on activities | Descriptives, T-test, ANOVA | Friend/ peer | Social participation | n/a | People with IDD have networks comprised of family members,<br>Those with IDD have less diverse networks | Yes; paired with neurotypical peer | |

*Table 3* Continued.

| Author and Year | Network survey or name generator | Types of tests run | Types of ties that were assessed | Dependent variable | Average number of ties | Outcomes linked to ties | Comparison group | Other |
|---|---|---|---|---|---|---|---|---|
| **Cunningham & Warschausky (2009)** | Social network inventory for children | Descriptives, Chi-square, T-test, Regression | Friend/ peer | Social functioning (networks, friendships, social adjustment) | For those with IDD M=7.61 (SD=.392),<br>Neurotypical M=12.53 (SD=6.56) p=<.001 | People with IDD have smaller networks,<br>People with IDD don't have friend networks | Yes; neurotypical peers | |
| **Hoyle & Serafica (1988)** | "people you know best" | Descriptives, Chi-square, ANOVA | Parental/familial, Friend/ peer, classmates; outside of school adults | Social status with ecological variables | Those with IDD received an average of .39 nominations compared to 1.26 of paired control. (p<.05)<br>.38 of their ties were reciprocal compared to .88 of peers. (not significant)<br>Those with IDD nominated 5.04 people on average compared to paired control of 3.83. (not significant)<br>Those with IDD nominated 3.74 family members on average compared to 2.17 of controls network (not significant) | Those with IDD received less nominations from peers;<br>Networks were not significantly different in size;<br>Interactions with peers didn't happen at home; | Yes; paired with neurotypical peer | Only white students |

*Table 3*. Continued

| Author and Year | Network survey or name generator | Types of tests run | Types of ties that were assessed | Dependent variable | Average number of ties | Outcomes linked to ties | Comparison group | Other |
|---|---|---|---|---|---|---|---|---|
| **Ouellette, Horner, Newton (1994)** | Social network analysis form (SNAF); name "people who are important to you" across 5 categories family, coworkers/ co-residents, people providing support, friends, neighbors/others | Descriptives | Parental/familial, Caregiver, formal/informal, Friend, others with IDD | Social integration and activity patterns to build social networks | Pre: M=17.4 Post: M=23;<br>Without formal relationships Pre: M=10.6 Post: M=15.8 | People with IDD have networks comprised of formal relationships,<br>Networks change over time with exposure to activities increasing the size of networks;<br>Adding friends is possible | No | Staff members helped answer if needed |
| **Ward, Atkinson, Smith, Windsor (2013)** | "who would you do something fun with?" & nature of relationship until exhaustion | Descriptives, Chi-square, ANOVA, | Friend, potential romantic relationships | Assess the acceptability and efficacy of program; interpersonal violence | Baseline: M=4.14<br>At program end M=7.06<br>10 weeks post: M=6.48<br>p=.002 between pre and 10 weeks post | Relationships don't change with geographic relocation,<br>Networks can grow over time through program participation | No | Process evaluation; Friendships and Dating Programs: U of Alaska Anchorage |

# CHAPTER III

# USING EGOCENTRIC NETWORK TO BETTER UNDERSTAND SOCIAL SUPPORT IN PEOPLE WITH DISABILTIES

## Introduction

Social support often found through personal relationships can be directly linked to one's quality of life (House et al., 1988). Social support can act both horizontally and vertically. Horizontally, social support allows people to "get by" in their current position, while it can also vertically provide social leverage for people to "move up" within their networks (Putnam, 2000). Research indicates that individuals who can access different types of sources of support experience better outcomes (e.g., emotionally, mentally, physically, educationally; Cauce et al., 1982; Cohen & McKay, 1984; Cohen & Wills, 1985; Cohen & Syme, 1985; de la Haye et al., 2012; House et al., 1988; Thoits, 1995; Uchino, 2006), and that people are "shaped, redirected, and constrained by the social context" in which they live (Coleman, 1988, pS96). For example, through different networks, people have the chance to secure employment (Barone et al., 1993), housing services (Tsemberis & Eisenberg, 2000), and other opportunities (Clauss-Ehlers & Wibrowski, 2007; Lippold & Burns, 2009). Similarly, people gain emotional support from their networks, allowing for attachments to form and providing stability and a sense of belonging (Hale et al., 2005). Additionally, those who receive emotional support— which fosters the experience of belonging and being valued— may have more positive self-evaluations and stronger self-efficacy (Cohen &

McKay, 1984). Individuals who can access tangible support such as money, food, or necessary resources through their networks may be less likely to experience stress (House, 1981).

Social support plays a role in our daily living, though it does not always have a positive impact. Those with negative perceptions of support from family and friends have higher incidence of depression (Young et al., 2005); whereas, people who are surrounded by relationships where they perceive strong social support show few signs of depression (Clara et al., 2003; Weber et al., 2010). Social isolation, or a lack of a social support network, has been linked to depression as well (Sakurai et al., 2020). Those who are considered different by societal standards (e.g., those with intellectual and developmental disabilities) are at an increased risk for social isolation and associated mental health struggles (Hussong et al., 2019).

One subgroup of the population that can especially benefit from social support is individuals with disabilities. There are many types of social support, but three types are instrumental for the success of young people with disabilities: 1) belonging support, 2) appraisal support, and 3) tangible support. Belonging support creates a sense of inclusion and that others are there for a person (Glanz et al., 2008; Kent de Grey et al., 2018). A sense of belonging can aid in less physical symptoms (Hale et al., 2005), decrease depression (Hagerty & Williams, 1999), and mitigate risk- behaviors (McNeely & Falci, 2004). Appraisal support, sometimes called informational support, is the supplying of information, advice, or suggestions that could benefit an individual (House et al., 1988). The ability to access this type of support equates to better health outcomes (Uchino, 2006), better life decisions (Niles, 1996), and student adjustment to changes in environment or circumstance (Malecki & Demaray, 2003). Tangible support is the provision of physical, financial, or material assistance (e.g., labor, goods; Kent de Grey et al., 2018). Tangible support is associated with better physical functioning (Woloshin et al., 1997), psychological well-being (Coffman, 2008; Friedman & King, 1994), and stress (Krause, 1986). Thus, having a robust support network where various types of support are provided across social connections can vastly improve the health and quality of life of individuals, particularly those with IDD.

## Social Network Analysis

Social network analysis (SNA) is a theoretical perspective and methodology that can be used to understand relationships and social processes that influence behavior and health (Wasserman & Faust, 1994). At the foundation, SNA assesses the relationships between people and the context in which they exist, instead of focusing on the individuals themselves. SNA posits social interactions drive personal action and belief, and can be a diffusion platform for information and goods to pass through social connections. Within the health field, SNA has been used to explore a wide range of issues including: exercise (Barclay et al., 2013; Leroux et al., 2012; Patterson et al., 2019; Patterson & Goodson, 2017), food intake (Barclay et al., 2013; Fletcher et al., 2011; Hutchinson & Rapee, 2007; Salvy et al., 2012), pro-social behaviors (O'Malley et al., 2012), risky behaviors (Chan et al., 2018; Ennett et al., 1999; Friedman, 2001; Meisel & Barnett, 2017), recovery and addiction (Best et al., 2018; Patterson et al., 2020), and social support (House et al., 1988; Skahill, 2002; Stokes, 1983; Thoits, 1995), among others.

### Social Support, Social Networks, and Intellectual and Developmental Disorders

Social capital and social support are instrumental in the success of young people who experience intellectual and developmental disorders (IDD). Literature suggests that individuals with disabilities have difficulty integrating into society, and engagement in community activities does not ensure support is provided or an individual is going to feel like they belong (Lippold & Burns, 2009; Myers et al., 1998). Friendship and other integration can help decrease loneliness, which is reported at a higher rate by those with IDD compared to their neuro-typical counterparts (Margalit, 2004; Sheppard-Jones et al., 2005). Loneliness and isolation are risk factors for abuse, exploitation, mental health disorders, and lower quality of life (Stancliffe et al., 2007). This suggests the importance of relationships on success and resource attainment, particularly for adults with IDD.

Compared to nondisabled adults, the social networks of adults with IDD tend to be smaller, consist of fewer friends (as opposed to family members or care takers), are less reciprocal, and contain a large proportion of service providers and formal relationships (Forrester-Jones et al., 2006). Children who experience disabilities have poorer social skills and lower-quality relationships even with those that they consider a best friend (Cunningham et al., 2007). For individuals with IDD living with their parents, most of their network members are other family members and networks are deeply embedded with those of the mother (Krauss et al., 1992).

Studies investigating the social networks of persons with IDD have mostly assessed quality of life for the individual, and focused on: (a) measurement of the degree of integration, inclusion, and participation in society, (Carter & Hughes, 2005; Hughes et al., 1998; McGaughey et al., 1995; Rossetti, 2011); (b) friendship and loneliness (Hill & Dunbar, 2003; Robertson et al., 2001; Stancliffe et al., 2007; Verdonschot et al., 2009); (c) factors that affect the degree of social inclusion (Perry & Felce, 2005; Robertson et al., 2001; Stancliffe et al., 2000); and (d) intervention studies that have identified strategies and methods that work to increase social inclusion (Amado et al., 2013; Hayden & Abery, 1994; Hughes et al., 1998; Smith, 2007). Most research focuses on the types of relationships (i.e., parents, support staff, friend) without delving into the unique properties of the dyads (e.g., value placed on relationship, specific support provided) and understanding what makes the support provider, recipient, and the relationship between them unique.

Because social support represents an underlying factor that impacts quality of life and mental health, SNA could provide insight into social support provision for people who have IDD. SNA has the ability to add the context surrounding support relationships that is currently missing from the literature. The study aims at understanding 1) what compositional patterns exist in egocentric support networks for adults with IDD enrolled in a career preparation program; 2) if the egocentric networks of adults who participate in a career preparation program change over time; and 3) if there are differences in network properties across three different types of support (i.e., do adults in the program tend to nominate the same people for all three types of support?)?

# Methods

## Participants and Procedures

Study participants (n=21) were adults with IDD recruited from an on-campus, one-year certificate program. The program is a career preparation program for adults with intellectual and developmental disabilities provided through the Center on Disability and Development at a large, southern, public university's College of Education and Human Development. All participants live independently, on and off-campus with complete freedoms. Additionally, to be admitted into the program, applicants must be their own legal guardian. However, for most, this is the first time to be out of the house from those who raised them, providing a unique time to collect social support data. They participate in one semester of coursework coupled with a semester-long practicum. The programmatic goal is for participants to earn a certificate that combines classroom instruction with practical career-building to become a Direct Support Professional (e.g., working with people with disabilities), Para-Professional working in schools, or Child Care Professional (*PATHS Certificate Program*, n.d.). During the first semester, a typical week consists of six classes that meet twice a week and one class that meets every other week. Additionally, participants have a five-hour block on Fridays with mandatory volunteer time and a mandatory one-hour library time. The certification groups take the majority of their classes separately, although there are two classes in which they are combined. The second semester of the program, participants are assigned to a practicum location. To be eligible for the study, participants had to be over 18 years old and enrolled in the program.

Data was collected between November 2019 and January 2020. The first round of data collection occurred in November 2019, two weeks before the end of the first semester, with a follow-up email a week later. The second round of data collection occurred the second week of January 2020, while participants were still at home on winter break.

At both data collection points, participants were provided via email a *Qualtrics* link so they could complete an online survey. This allowed participants to take all of the time they needed and use assistant devices to read and understand the surveys. There was no compensation for completing the study to avoid any feelings of coercion. Once the participant opened the *Qualtrics* link, they were provided with the informed consent document that included the study purpose, risk, benefits, and their ability to withdraw at any time. They then provided their electronic informed consent by clicking a button agreeing to participate. The study was approved by the Institutional Review Board prior to data collection.

## Egocentric Network Analysis

There are two different approaches to SNA. One approach is whole network analysis where an entire group of people (nodes) is examined to observe how parts of the network and structure influences an outcome of interest (Valente, 2010). The other approach is egocentric network analysis. This approach focuses on individuals (ego) and their immediate social interactions (alters) (Perry et al., 2018). The foundational belief within egocentric network analysis is that people function within their own central environment, and have relationships across varying social groups. For example, the persons that occupy someone's personal network may consist of family members, coworkers, teammates, co-members of organizations, or friends from past experiences, all of which come from different social groups the ego is a part of. Thus, egocentric network analysis allows for the investigation of a sample of individuals' personal networks, comprised of alters from varying social groups and experiences (i.e., alters do not have to belong to the same social networks to be considered part of an egocentric network). The individual networks are created by the ego, and thus unique to each ego, but also a reflection of the ego (Perry et al., 2018). The goal of egocentric network analysis is to predict outcomes based on connections and characteristics of the alters, while also understanding why egos build the networks they do. This study utilized egocentric network analysis to explore the individual networks of a group of young adults with IDD across different types of social support and how the networks differ in composition and roles.

In order to complete an egocentric network analysis, each participant provides attribute data, name generator data, and name interpreter data. Attribute data are information about the individual, including demographic and behavioral information. The name generator is a technique in which each participant (the ego) is presented a series of questions designed to generate names or nicknames of people in their life (i.e., alters; Perry et al., 2018). For example, egos could be asked to list "up to five people you feel close to", or some other question that would generate a list of names in their life. The respondent then answers questions about each alter provided through the name generators called name interpreters. These types of questions qualify the ego's relationship with the alter and provides information about each alter (e.g., gender of alter, length of relationship to the alter, type of relationship to the alter, trust levels).

Traditional egocentric network research uses a single name generator and allows respondents to nominate a set of alters according to the single name generator. The question used most often to elicit names is “with whom do you discuss important matters?” The ego would then provide multiple names to the single question (Borgatti et al., 2013). Typically, the number of nominations is capped, which can over or underestimate a network (Valente, 2010). This study took a more innovative name generator approach by using multiple name generators. A multiple name generator approach is unique because it allows for participants to nominate one or two close ties across multiple questions, capturing a broader representation of the ego’s personal network. This approach provides insight to particular roles people fill in individuals’ lives and potentially a more complete understanding of the core network around a person.  Initial findings suggest multiple name generators are a more thorough way to assess size, density, and composition of personal networks compared to the traditional single name generator (Marin & Hampton, 2007).

After collecting name generator and name interpreter data, several types of egocentric network measures need to be calculated. These network measures include alter analysis and ego-alter similarities. Alter analysis is a conceptualization of the types of alters an ego has in their network (Borgatti et al., 2013; Perry et al., 2018). Alter analysis can be calculated through central tenancy or heterogeneity and the attributes of the ego are left out of the analysis. The results provide counts or proportions of individual networks that fall into different categories, along with how evenly those are distributed (Borgatti et al., 2013; Valente, 2010). The ties can be weighted or unweighted (i.e., values can be given to ties to show intensity or be binary; Valente, 2010). For example, if we look at the gender composition in a network, a proportion of the genders would be presented, but the results would be independent of the ego. The data shows how similar (homogenic) or dissimilar (heterogenic) a group can be (Borgatti et al., 2013; Valente, 2010). Ego-alter similarities is a measure of the degree to which alters are similar to the ego and is indicated through proportions (Borgatti et al., 2013; Perry et al., 2018). Ego-alter analysis suggests the homophily or influence that alters may have on an individual because behaviors can be transmitted across a group of people (Borgatti et al., 2013). Homophily is the similarities of an ego and alter and is represented by the percentage of the alters have the same attributes (Perry et al., 2018). Ego-alter similarity reflects the degree to which an ego interacts with those like them.

## Measures

Participants provided demographic data and network data via an online survey. Demographic data included gender, age, sexuality, and IDD diagnosis.

**Egocentric network data.** To collect egocentric network data, participants (the ego) provided a name (the alter) to each of nine name generator questions. Name generators were designed to assess three types of support being measured (i.e., appraisal, tangible, and belonging). For example, one question used to assess tangible support was "if you needed $20, who would you ask for money?" Each subtype of support used three proxy questions to assess who would provide the individual supports. All nine questions were derived from the Interpersonal Support Evaluation-short version survey (Cohen et al., 1985), and egos provided a single name for each of the nine questions. Egos were allowed to provide the same name across multiple name generators if that person provided them multiple types of support. See *Table 4* for all items measuring appraisal, belonging, and tangible support.

After answering name generator questions, individuals (i.e., egos) provided the following information for each nomination (i.e., alter) via name interpreter questions: gender, relation, if they trust the person, and if they met them through the PATHS program. The choices for gender were: male, female, and other. The options for relationship were parent, sibling, other family member, caregiver/support staff, friend, doctor, teacher, and other. Participants denoted whether they trusted each alter fully, a little, or not at all. Lastly, egos were asked if they met the alter through the program (yes or no). A formal or informal relation variable was created from the relationship variable, with caregivers, doctors, and teachers grouped as formal relationships, and all others defined as informal. The formal group was conceptualized to be those who have job descriptions that require interaction with individuals.

## Analysis

The statistical program, E-Net (Borgatti, 2006), was used to create egocentric network variables using name interpreter data. For alter analysis, compositional variables were created for the gender, program participation, relationship, and trust variables. Compositional variables denote the percentage of nominated alters in each egocentric network that fall into each category within the variable (Perry et al., 2018).

For tie analysis, homophily was created on the gender variable. Homophily is represented by the percentage of the alters that are the same gender as the ego (Perry et al., 2018). Descriptive statistics were conducted using SPSS version 26.

## Results

### Descriptive Statistics

The surveys were sent to 21 individuals—13 responded to each of the surveys with 7 participants answering both surveys and 4 answering neither. During the first round of data collection, the sample was comprised of mostly females (69.2%, n=9) and 76.9% of participants identified as straight (n=10). Diagnoses were split up between non-specified intellectual diagnosis (30.8%, n=5), Autism (15.4%, n=2), and Attention Deficit Disorder (ADD; 7.7%, n=1). The other five participants had no diagnosis or did not know their diagnosis. The average score for the PHQ-8 was 6.5 (SD=4.97) with the majority of participants (69.2%, n=9) scoring in the normal range and four scoring in the "moderate depression" range. None were considered severely depressed. Three participants reported that their depression caused daily living to be very difficult from depression.

At the second round of data collection, nine females (69.2%) responded and all but one participant identified as straight (92.3%, n=12). Diagnoses were slightly different than the first round of data collection with almost half (46.2%, n=6) of participants having a non-specified intellectual disability. One individual identified as experiencing ADD and another identified as being Autistic. Two participants (15.4%) scored in the moderate depressive range and 23.1% (n=3) found their depression caused much difficulty to daily living. *Table 5* displays all sample characteristics from the two time points.

### Egocentric Support Networks

**Belonging support.** During time point one, participants nominated on average 2.46 unique individuals that provide them belonging support. Egos nominated almost one unique male (0.92) and 1.39 females in their personal networks. The majority of nominations were friends (61.5%, M=2.31, SD= 1.60), followed by parents (30.8%, M=.54, SD=.66), a sibling (5.1%, M=.15, SD=.38), and other (2.6%, M=.08, SD=.28). These numbers also indicate that no formal relationships were nominated during time point 1. Of the 2.46 unique individuals nominated (SD=.78), 1.46 of them were in the PATHS program (51.3%, SD=1.19), and 2.15 were highly trusted (87.2%, SD=.90). Compositionally, the majority of alters nominated were females (71.8%) and homophily for gender was 33% (i.e., 33% of nominations were the same gender as the ego).

At the second time point, participants averaged 2.38 unique nominations for belonging support (SD=.65), with an average of .78 males (SD=.92) and 1.62 females (SD=.96) present within egocentric networks. There were no siblings nominated during this time-point, but caregivers (5.1%, M=.08, SD=.28) were nominated. Formal relationships increased at time point two (5%, M=.08, SD=.28). An average of 1.62 friends were nominated (59%, SD=.96) and .35 parents (20.5%, SD=.65). Egos highly trusted an average of 2.31 nominations (97.4%, SD=.60). Females comprised two thirds of networks and 28.6% of alters were the same gender as the ego. *Table 6* provides a comprehensive summary of the belonging support egocentric networks.

**Appraisal support.** Participants nominated an average of 2.46 (SD=.66) unique individuals who provide them appraisal support in time point one. An even number of males (M=1.26, SD=.83) and females (M=1.26, SD=.73) were nominated for appraisal support, on average. The majority of nominations were friends (43.6%, M=1.77, SD=1.79) followed by parents (37.2%, M=.54, SD=.66), a sibling (5.1%, M=.15, SD=.38), teachers (6.4%, M=.15, SD=.38), and other family members (5.1%, M=.15, SD=.38). There was an average of .23 formal relationships nominated (8%, SD=.44). Of the 2.46 unique individuals nominated, 1.23 of them were in the PATHS program (41%, SD=1.17) and 1.77 were highly trusted (74.4%, SD=.83). Networks were primarily composed of females (56.4%), and homophily for gender was 23.1%.

At the second time point, participants averaged 2.54 unique nominations (SD=.52) with an average of 1.08 males (SD=1.03) and 1.46 females (SD=1.05). An average of 1.31 friends were nominated (48.7%, SD=.95), along with .77 parents (34.6%, SD=.83) and .23 other family members (9.0%, SD=.44). With doctors and teachers nominated at time point two, formal relationships averaged .15 (5%, SD=.38). Egos highly trusted an average of 2.23 nominations (94.9%, SD=.60) and only an average of .85 nominations were in the PATHS program (33.3%, SD=.69). Females comprised 53.8% of networks and 35.9% of alters were the same gender as the ego. *Table 6* provides a comprehensive summary of the appraisal support egocentric networks.

**Tangible support.** During time point one, egos nominated an average of 2.38 unique alters who provided them tangible support. These alters were comprised of 1.15

unique males (SD=.69) nominated on average, and 1.23 females (SD=.60). The majority of nominations were parents (61.5%, M=1.23, SD=.44), followed by friends (19.2%, M=.62, SD=.51), a sibling (7.7%, M=.31, SD=.63), and other family members (6.4%, M=.31, SD=.85). There were no formal relationship nominations. Of the 2.38 unique individuals nominated, .31 of them were in the PATHS program (8.9%, SD=.48) and 1.69 were highly trusted (66.7%, SD=.63). Similar to belonging and appraisal support, networks were primarily comprised of females (55.1%) and homophily for gender was 16.3%.

At the second time point, participants averaged 2.46 unique nominations (SD=.66) with an average of 1.08 males (SD=.86) and 1.38 females (SD=.65). An average of 1.15 parents were nominated (47.4%, SD=.55) and .77 friends (28.2%, SD=.60), followed by an average of .23 siblings (7.7%, SD=.44). Formal relationships increased to average .08 (3%, SD=.28). Egos highly trusted 2.08 nominations (85.9%, SD=.76) and .54 were a part of the PATHS program (20.5%, SD=.66). Females comprised 61.5% of networks and 18.8% of alters were the same gender as the ego. *Table 6* provides a comprehensive summary of the tangible support egocentric networks. *Tables 7 and 8* provide an overview of the cumulative answers of all respondents across the three types of support.

## DISCUSSION

The purpose of this study was to examine the composition of social networks for three different types of social support across two time points within a group of adults who experience IDD in a career preparation program. Results indicate observed distinctions in attribute composition for the type of support being provided (i.e., different people provided specialized support for this network) and slight variances across time.

## Belonging Support

At both time points, friends were mostly nominated, with family members only making up around a quarter of networks (35.1% and 20.5%) for belonging support. Belonging is the support an individual receives through dedicated time with others and feeling accepted (Mussida & Sciulli, 2019). Additionally, more than half of the network was comprised of others in the PATHS program, and egos nominated more than two unique people across the three name generator questions (i.e., participants tend to have more than one person providing them belonging support). These findings are contradictory to research in multiple ways. First, typically, those with IDD have small networks, comprised of mainly family and formal relationships (Kennedy et al., 1989; Krauss et al., 1992; Sheppard-Jones et al., 2005). Second, these relationships are typically unstable and superficial (Cunningham et al., 2007). Last, those who have IDD are given social support by others, but are unlikely to be the providers of support.

These results suggest that for belonging support, egos are finding a sense of acceptance with their friends who are a part of the same program as them. The composition of these networks indicates that having the personal freedom and autonomy—by being in the program and provided independence in who they spend time with—allows for a sense of belonging independent of family and formal relationships. In other literature with traditional college freshmen, those who joined extracurricular activities and were provided support through said activities had less stress and better life satisfaction (Civitci, 2015). Traditional college freshmen are likely going through similar life changes as the PATHS participants (e.g., newfound independence. The participants are also able to provide support to each other, an exchange that is not well studied in the literature (Ouellette et al., 1994).

Between the two time points, there was little observed differences in composition of alters. Even though the average number of friends nominated decreased at time point two, the network composition percentage stayed the same. Composition of parents nominated decreased by a third, meaning that even though the egos were at home during the second point of data collection, where we can assume they were with their parents, they did not feel an increased sense of receiving belonging support from parents. Network composition of other PATHS program participants increased; so even though they were not physically with program friends, they felt supported by them. This finding provides insight into the fact that geographic proximity is not critical to perceived belonging support overtime within this group of egos, unlike what previous literature has found (Mulder & Wagner, 2012). This group of participants had the opportunity to create strong bonds before they parted from their peers. Additionally, for gender homophily, about two thirds of the nominations were not the same gender as the ego at both time points. This means that not only were they nominating mostly friends, but friends of a different gender. There could be romantic relationships developing through the participation in the program and were sustained, even after winter break (Hwang et al., 2007; Siebelink et al., 2006). Those with IDD have difficulty in distinguishing between friendship and romantic relationships, but have immediate desire for romantic relationships (Heifetz et al., 2020). With such a desire and inability to differentiate relationships, more romantic relationships could have formed within the program participants. Further research needs to explore romantic relationships between those with IDD and the salience of these relationships.

## Appraisal Support

Network role composition for appraisal support was mainly split between family members and friends. This means that when egos needed advice or suggestions about their personal lives, they nominated either family members or friends. While formal relationships (e.g., paid caregivers, doctors, teachers) were represented the most for appraisal support compared to the other types of support, formal relationships still made up a small proportion of networks. This finding could be due to the sample. Literature suggests that the more impact on daily functioning an intellectual or developmental disability has on a person, the more personal networks tend to be composed of formal relationships (Forrester-Jones et al., 2006; Kennedy et al., 1989). The participants for this study live independently and do not have a guardian, indicative of minimal to no special need for reliance on caregivers or other formal relationships for living. If the sample included those that still had legal guardians or needed more specialized assistance, then findings may have paralleled previous research.

At both time points, the percent composition of friends in the network was similar; however, the composition of PATHS participants decreased at the second data collection. This shows that friends were perceived as a trustworthy provider for appraisal support, but the type of friend changed from a PATHS participant to others when they were gone for break. This demonstrates that spatial proximity has an effect when it comes to appraisal support, and these relationships might not be as stable in providing appraisal support, particularly when they are not in the same location. Previous literature pertaining to in-person verses online support groups indicate that for intimate support, like appraisal, in-person interactions are more impactful for support to be felt compared to electronic relationships (Johnson, 2015). If appraisal support is wanting to be maintained through this program, participants may need to be in kept close physical proximity.

Trust increased in the network by 20% between time points. The temporality and change in location allowed egos to feel like they had more trustworthy sources of appraisal support. More research is needed to understand what caused this change. The main change between the two time points is the percentage of people in the network from the PATHS program. People at home could be the natural trusting relationships because they are individuals who have been around participants all their life (Bengtson, 2001), instead of those in the program who they had only know for a few months.

### Tangible Support

Familial support was the most vital type of relationship in perceived provision of tangible support. This can take the form of provisions of money, a ride, food, or any other tangible good or service. Over two-thirds of tangible support networks were comprised of family members (i.e., parents, siblings, other family members). Previous literature indicates family as a key provider of tangible support for any person (Coffman, 2008; Hirschman & Bourjolly, 2005). Like appraisal support, parents and other family members were who predominately provided that support (Bengtson, 2001). Support pathways created in childhood could have continued into young adulthood. If participants grew up with limited support provision from peers and instead turned to friends and family, then these supports could continue into early adulthood. Friends and other PATHS participants played a very small role in tangible support provision in this sample, though both increase at the second time point. Friends and other PATHS participants were mainly nominated if the ego needed a ride. This finding could occur because asking for money and help if you are sick are more intimate types of support; whereas, a ride is not as demanding on the person providing support.

Egos trusted their alters the least amount when it comes to tangible support. Between the three types of social support, tangible support could be seen as the least personal. For both appraisal support and belonging, there has to be a personal connection before a person asks for advice or feels like they belong. We live in a society today where tangible acts are completed by strangers (i.e., ride sharing, grocery shopping, money loaning, house renting). This societal norm may have permeated into the beliefs of the egos. In both of hypothetical ride questions, an ego named a ride sharing company. There is no literature to explain why this trust phenomenon may occur.

## Limitations

Findings of the study are not generalizable because of convenience sampling. Every individual network is unique, meaning replication with the same or a similar group of people could yield different results (Valente, 2010). A larger sample size and more rigorous data collection could provide better insight into the phenomenon. This study would need to be repeated multiple times, across similar networks, to create a more generalized and conclusive understanding of social support networks among adults with IDD. Another limitation to this study is the sample size at each time point (n=13). A sample size this small limits statistical power needed to run t-tests and chi-square analyses to conclude differences across time and types of support.

## Implications for Research and Practice

Because literature indicates that relationships for those with IDD are considered less stable and do not last as long as their neurotypical counterparts, measures to ensure stability and longevity are important. This study indicates that relationships with peers and others who experience IDD is possible. With this knowledge, more programs should focus on the bringing together of young adults with IDD and allowing belonging support to thrive since appraisal and tangible support seems relatively stable to previous relationships. Typically, those with IDD do not have the opportunities to grow their network size (Forrester-Jones et al., 2006), thus keeping networks mostly composed of family members and their associations. Findings from this study provide evidence that the PATHS program allowed egos to grow their network beyond those they grew up with. It also allowed them to create relationships on their own, without the facilitation of family members.

Future researchers should follow up with program participants several months after the program has ended. Through this method, the understanding of geographic proximity on support provisions could be better understood. Additionally, researchers should continue using multiple name generators to discover the differences in attributes for social support provision instead of a generic name generator like “who helps you in your life.” This method provides a holistic picture of support, while assessing size and composition more effectively. Other types of support could be assessed in future research as well (i.e., emotional, esteem, invisible).

## Conclusion

Social network analysis provides a theoretical framework and methodology for understanding social support and the differences between types of support. By only observing who provides individuals with IDD support, the knowledge of the phenomenon would be limited. Through SNA and parsing out the differing types of support, a more holistic and rich understanding of social support is possible. Network variables provide clarity to the context of relationships. Additionally, understanding the differences between types of support could provide insight that could help in social capital and support being intentionally generated among this population (Pronyk et al., 2008). This study provides preliminary evidence that individuals with IDD, who historically struggle with receiving the same social capital through networks as their neuro-typical counterparts, benefit greatly from programs such as PATHS, where they give and receive various types of social supports within their peer networks.

*Table 4*. Question set for each item within the three types of support

| Type of support | Question |
|---|---|
| Belonging | If you were to go on a trip for a day, who would you invite to go with? |
| | If you wanted to go to the movies, who would you invite? |
| | If you wanted to go to lunch, who would you invite? |
| Appraisal | Who would you talk to if you needed to share private worries or fears? |
| | If you needed advice for handling a problem with your family, who would you talk to? |
| | If you needed some suggestions on a personal problem, who would you talk to? |
| Tangible | If you were sick, who would help you with chores? |
| | If you needed a ride somewhere, who would you ask? |
| | If you needed $20, who would you ask for money? |

*Table 5.* Sample characteristics of 21 individuals involved in a career preparation program

| | Time 1 (n=13) | | Time 2 (n=13) | |
|---|---|---|---|---|
| Variable | N | % | N | % |
| Females | 9 | 69.2 | 9 | 69.2 |
| Sexuality | | | | |
| Straight | 10 | 76.9 | 12 | 92.3 |
| Gay/Lesbian | 1 | 7.7 | 0 | 0 |
| Bisexual | 1 | 7.7 | 0 | 0 |
| Other | 1 | 7.7 | 1 | 7.7 |
| Diagnosis | | | | |
| None/Unknown | 5 | 38.5 | 5 | 38.5 |
| ADD | 1 | 7.7 | 1 | 7.7 |
| Autism | 2 | 15.4 | 1 | 7.7 |
| Non-specified intellectual | 4 | 30.8 | 6 | 46.2 |
| Depression | 6.5<br>(4.97) | | 6.15<br>(2.79) | |
| Normal (0-9) | 9 | 69.2 | 11 | 84.6 |
| Moderate (10-19) | 4 | 30.8 | 2 | 15.4 |
| Severe (20+) | 0 | 0 | 0 | 0 |
| Daily difficulty from depression | | | | |
| Not difficult at all | 4 | 30.8 | 4 | 30.8 |
| Somewhat difficult | 6 | 46.2 | 6 | 46.2 |
| Very difficult | 3 | 23.1 | 3 | 23.1 |

*Table 6*. Individual composition of egocentric networks across type of support

| | Belonging | | Appraisal | | Tangible | |
|---|---|---|---|---|---|---|
| | Time 1 | Time 2 | Time 1 | Time 2 | Time 1 | Time 2 |
| Gender | | | | | | |
| Male | .92 | .78 | 1.23 | 1.08 | 1.15 | 1.08 |
| Female | 1.39 | 1.62 | 1.23 | 1.46 | 1.23 | 1.38 |
| Relationship | | | | | | |
| Parent | .54 | .35 | .54 | .77 | 1.23 | 1.15 |
| Sibling | .15 | - | .15 | .15 | .31 | .23 |
| Other family | - | .08 | .15 | .23 | .31 | .15 |
| Caregiver | - | .08 | .08 | - | - | .08 |
| Friend | 2.31 | 1.62 | 1.77 | 1.31 | .62 | .77 |
| Doctor | - | - | - | .08 | - | - |
| Teacher | - | - | .15 | .08 | - | - |
| Other | .08 | .23 | - | - | .08 | .08 |
| Definitely Trust | 2.15 | 2.31 | 1.77 | 2.23 | 1.69 | 2.08 |
| In PATHS | 1.46 | 1.69 | 1.23 | .85 | .31 | .54 |
| Formal relationships | - | .08 | .23 | .15 | - | .08 |
| Unique nominations | 2.46 | 2.38 | 2.46 | 2.54 | 2.38 | 2.46 |
| Total nominations | 32 | 31 | 32 | 33 | 31 | 32 |
| Composition (%) | | | | | | |
| Gender (female) | 71.8 | 66.7 | 56.4 | 53.8 | 55.1 | 61.5 |
| In PATHS | 51.3 | 61.5 | 41.0 | 33.3 | 8.9 | 20.5 |
| Parent | 30.8 | 20.5 | 37.2 | 34.6 | 61.5 | 47.4 |
| Sibling | 5.1 | - | 5.1 | 2.6 | 7.7 | 7.7 |
| Other family | - | - | 5.1 | 9.0 | 6.4 | 11.5 |
| Caregiver | - | 5.1 | 2.6 | - | 2.6 | 2.6 |
| Friend | 61.5 | 59.0 | 43.6 | 48.7 | 19.2 | 28.2 |
| Doctor | - | - | - | 2.6 | - | |
| Teacher | - | - | 6.4 | 2.6 | - | - |
| Other | 2.6 | 15.4 | - | - | 2.6 | 2.6 |
| Definitely Trust | 87.2 | 97.4 | 74.4 | 94.9 | 66.7 | 85.9 |
| Formal | - | 5.0 | 8.0 | 5.0 | - | 3.0 |
| Homophily | | | | | | |
| Gender | 33.0 | 28.6 | 23.1 | 35.9 | 16.3 | 18.8 |

*Table 7*. Cumulative answers of egocentric networks at time point 1

| | | Female | Parent | Sibling | Other family | Caregiver | Friend | Doctor | Teacher | Other | Definitely Trust | In PATHS |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Belonging | Trip | 10/13 | 5/13 | 1/13 | - | - | 6/13 | - | - | 1/13 | 11/13 | 6/13 |
| | Movies | 8/13 | 3/13 | - | - | - | 10/13 | - | - | - | 11/13 | 8/13 |
| | Lunch | 10/13 | 4/13 | 1/13 | - | - | 8/13 | - | - | - | 12/13 | 6/13 |
| Appraisal | Worries | 9/13 | 5/12 | 1/13 | - | - | 7/12 | - | - | - | 12/13 | 5/13 |
| | Advice | 6/13 | 4/13 | - | 2/13 | - | 6/13 | - | 1/13 | - | 13/13 | 6/13 |
| | Suggestion | 6/12 | 5/12 | 1/12 | - | 1/12 | 4/12 | - | 1/12 | - | 9/12 | 5/12 |
| Tangible | Sick | 9/11 | 8/11 | 2/11 | - | - | 1/11 | - | - | - | 9/11 | 0/11 |
| | Ride | 6/13 | 3/13 | 1/13 | 2/13 | 1/13 | 5/13 | - | - | 1/13 | 9/13 | 3/13 |
| | Money | 5/13 | 12/13 | - | - | - | 1/13 | - | - | - | 12/13 | 0/13 |

*Table 8*. Cumulative answers of egocentric networks at time point 2

| | | Female | Parent | Sibling | Other family | Caregiver | Friend | Doctor | Teacher | Other | Definitely Trust | In PATHS |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Belonging | Trip | 9/13 | 4/13 | - | - | 1/13 | 6/13 | - | - | 2/13 | 12/13 | 7/13 |
| | Movies | 10/13 | 2/13 | - | - | 1/13 | 8/13 | - | - | 2/13 | 13/13 | 7/13 |
| | Lunch | 7/13 | 2/13 | - | - | - | 9/13 | - | - | 2/13 | 13/13 | 10/13 |
| Appraisal | Worries | 6/13 | 4/13 | - | 1/13 | - | 8/13 | - | - | - | 12/13 | 5/13 |
| | Advice | 6/12 | 4/12 | - | 2/12 | - | 5/12 | - | 1/12 | - | 11/12 | 4/12 |
| | Suggestion | 8/13 | 5/13 | 1/13 | - | - | 6/13 | 1/13 | - | - | 13/13 | 4/13 |
| Tangible | Sick | 7/12 | 5/12 | 2/12 | 1/12 | - | 4/12 | - | - | - | 11/12 | 4/12 |
| | Ride | 9/12 | 2/12 | 1/12 | 1/12 | 1/12 | 6/12 | - | - | 1/12 | 11/12 | 3/12 |
| | Money | 6/13 | 11/13 | - | 1/13 | - | 1/13 | - | - | - | 10/13 | 1/13 |

# CHAPTER IV

# USING SOCIOMETRIC NETWORK ANALYSIS TO UNDERSTAND SOCIAL SUPPORT WITHIN A GROUP OF YOUNG ADULTS WHO EXPERIENCE INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

## Introduction

Participation in postsecondary education (PSE) can have a positive impact on securing future employment and increase the likelihood of successful independent living (Zhang et al., 2018). High schools and other alternative education programs have begun creating school-to-work programs to provide work experience and hands-on-learning to prepare students for the workforce. Unfortunately, these programs are not fully inclusive and often do not provide special assistance for students with disabilities, which make up an increasing proportion of those in schools (Burgstahler, 2001). Due to this gap, career preparation programs for those who have intellectual and developmental disabilities (IDD) have opened in secondary education over the last three decades (Horn & Berktold, 1999). PSE programs aim to equip those with IDD with life skills, college preparation, professionalism, and field based experience (Katsiyannis et al., 2009; *PATHS Certificate Program*, n.d.; Zhang et al., 2018). Students who experience IDD benefit from these types of programs equally, if not more, than their neurotypical peers (Burgstahler, 2001; Johnson & Rusch, 1993; Lowry, 1990). In 2019, the fact that only 30.9% of adults (18-64 years old) with disabilities work full or part-time, compared with 76.4% of those without disabilities, makes creating employment programs for those with disabilities all the more necessary (U.S. Bureau of Labor Statistics, 2020). Career preparation programs have the ability to not only bring together those with IDD and ready them for the workforce, but potentially create support networks between the participants. In fact, many programs state they increase peer support, though they do not measure change at the interpersonal level (Gesell et al., 2013; Golden & Earp, 2012)

Social relationships are important for all people to feel supported and have access to resources (Putnam, 2000). For people who have IDD, quality of life has been linked to social support; however, mere inclusion into a space with a group of people does not mean that support occurs (Myers et al., 1998). Embeddedness within the community has to be more intentional for those with an IDD than their neurotypical peers. For people with disabilities, relationships are even more essential, but can be difficult because of increased difficulty with social skills and lower-quality relationships compared to their "typical" developing peers (Cunningham et al., 2007). This issue is compounded because those with IDD have higher rates of isolation (Margalit, 2004; Sheppard-Jones et al., 2005). Isolation is not only a precursor to mental health disorders (House et al., 1988; Stancliffe et al., 2007) but those with IDD experience anxiety, depression, and suicidal tendencies at higher rates than the rest of the population (Huntington & Bender, 1993; Maag & Reid, 2006; Schreurs et al., 2002). Healthy social relationships can decrease depression, stress, and anxiety (Cohen, 2004; Kawachi, 2006) Understanding the social relationships and the resources accessed through them can be helpful in bettering mental health outcomes in this population.

## Social Capital

L. J. Hanifan, a public educator, was the first to coin the term *social capital*. Social capital was identified as goodwill, fellowship, mutual sympathy, and social interaction among a group of individuals and families who make up a social unit and he created the construct to indicate the importance of community engagement on education (Hanifan, 1916). Social capital was later expanded to other disciplines (e.g. sociology, psychology, health; Ahern & Hendryx, 2003; Berkman et al., 2000; House et al., 1988; House, 1981; Kushner & Sterk, 2005), though foundationally, maintains the concept that participation in groups can produce positive outcomes and experiences for individuals. For example, people who perceive that they have strong social support from others have better mental health outcomes (Clara et al., 2003; Weber et al., 2010). From social capital came social support (Putnam, 2000). It is the support provided through relationships that people leverage daily to get by within their same social position (i.e., acting horizontally); instead of social leverage, which allows individuals to get ahead and move vertically (Lukasiewicz et al., 2019).

Research indicates that individuals who can access different types of support through their relationships experience better outcomes (e.g., emotionally, mentally, physically, educationally; Cauce et al., 1982; Cohen & McKay, 1984; Cohen & Wills, 1985; Cohen & Syme, 1985; de la Haye et al., 2012). Through different networks, people have the chance to secure employment, housing services, and other opportunities (Barone et al., 1993; Clauss-Ehlers & Wibrowski, 2007; Lippold & Burns, 2009; Tsemberis & Eisenberg, 2000). Emotional support allows for attachment to form and provides stable relationships and a sense of belonging for people (Hale et al., 2005). Emotional support can also result in positive self-evaluation and self-efficacy for the individual (Cohen & McKay, 1984). Individuals who can access tangible support, such as money, food, or necessary services, may be less likely to experience stress (Coffman, 2008; Friedman & King, 1994; Hirschman & Bourjolly, 2005). Access to appraisal support can enhance one's ability to make informed decisions and process their problems with other people (Glanz et al., 2008).

When forming relationships, and as a result accessing social capital and support through networks, those with IDD typically have less connections and fewer peers. Instead, they are often connected to family members and formal relationships (i.e., caregivers, service providers, and other paid staff; Forrester-Jones et al., 2006). For example, when adults are still living at home with their parents, support and social interactions tend to be with family members and are deeply rooted in the networks of the mother (Krauss et al., 1992). Additionally, research shows that children who have IDD have poorer social skills compared to their peers and possess lower-quality relationships even with those that they consider a best friend (Cunningham et al., 2007). These relationships are usually unidirectional when it comes to support, meaning the individual takes, but does not provide support back. While some studies investigate the relationships between persons with an IDD and their family members and friends, less has considered the interactions between and among those who have IDD.

## Social Network Analysis

Social network analysis (SNA) can acts as both a theory and method to examine the interaction between relationships and social processes and their impacts on behavior (Wasserman & Faust, 1994). Social network analysis has been used in a variety of fields including biology, animal science, neurology, and sociology, but in essence observes the connections between two relational units (e.g., people, organizations, cells; Valente, 2010; Wasserman & Faust, 1994). At its foundation, SNA assesses the relationships between people and the context in which they exist, instead of focusing on the individuals themselves. According to network theory, social interaction drives personal action and belief and should therefore be a focus within analyses.

There are two types of social network analysis: sociometric, or whole network, and egocentric. In sociometric network analysis, an entire group of people (nodes) is examined to observe how parts of the network and structure influences an outcome of interest. The network is bounded within set specifications (e.g., group, neighborhood, classroom), which can impact sampling techniques and how data is collected (Wasserman & Faust, 1994). Once boundaries are set, data should be collected from all nodes within the inclusion criteria to ensure full understanding of the network structure and positions. Within sociometric network analysis, the individual characteristics of the node are not the main focus, like in linear data analysis, but instead the interactions of the dyads are the focus of analysis (Wasserman & Faust, 1994). In egocentric network analysis, the individual (ego), and the people the ego surrounds them self with, is the main point of interest and the focus of analysis (Perry et al., 2018). For egocentric networks, egos are sampled, and therefore just like traditional statistics, independence within the data is assumed (e.g., there is an assumption that participants do not know each other/are not interdependent).

Social network analysis allows for the measurement of various node- and network-level measurements that often influence health behaviors and outcomes (Borgatti et al., 2013). Node-level measurements pertain to individuals or nodes, where each node receives a unique score for node-level measures. An example would be the centrality of a node, or the level of prestige an individual has within the network (Valente, 2010). So, although the measure is about in individual, the analysis still incorporates the larger structure of the network and relation to other nodes. Network level measurements describe the network structure as a whole. An example of a network level variable is density, or the extent to which the network is connected (Valente, 2010). Even though a single node may skew the overall density by being highly connected, the final analysis would indicate the structure of the network as a whole, and therefore all nodes within an overall network contribute to an overarching network-level score.

Social network analysis has been used to study a multitude of health issues including happiness (Bollen et al., 2011; Brim, 1974; Fowler & Christakis, 2008), pregnancy (Boyce et al., 1985; Jorgensen et al., 1980; Kingsbury et al., 2018), smoking (Ennett et al., 2008; Ennett & Bauman, 1993; Mercken et al., 2012), exercise (Barclay et al., 2013; Leroux et al., 2012; Patterson et al., 2019; Patterson & Goodson, 2017), and social support (House et al., 1988; Skahill, 2002; Stokes, 1983; Thoits, 1995). While social networks have been explored among persons with IDD (i.e., studies have considered who persons with IDD tend to connect with and be socially tied to), social network analysis as a methodology has not yet been employed in this population. The primary aims of these existing studies were to understand the degree of social integration (Carter & Hughes, 2005; Hughes et al., 1998; McGaughey et al., 1995; Rossetti, 2011); friendship and loneliness (Hill & Dunbar, 2003; Robertson et al., 2001; Stancliffe et al., 2007; Verdonschot et al., 2009); factors that are associated with degree of social inclusion (Perry & Felce, 2005; Robertson et al., 2001; Stancliffe et al., 2000); and interventions to increase social inclusion (Amado et al., 2013; Hayden & Abery, 1994; Hughes et al., 1998; Smith, 2007) among adults with IDD. However, node- and network-level measures that relate to various outcomes in this population are yet to be determined.

Given the paucity in studies on the social interactions among adults with IDD, particularly from a network perspective, this study aims to investigate whether network variables were associated with depression and social support among a group of young adults who experience IDD using sociometric network analysis. In doing so, we will attempt to answer the following research questions: 1) How effective was a PSE program in creating social support relationships amongst participants and 2) Were certain positions or patterns within the whole network associated with depression?

## Methods

### Participants and Procedures

Study participants were recruited from an on-campus, one-year certificate program. The Postsecondary Access and Training in Human Services (PATHS) program is a career preparation program for young adults who experience intellectual and developmental disabilities (IDD) provided through the Center on Disability and Development at a large, southern, public university's College of Education and Human Development. The participants take a semester of coursework, comprising of six classes that meet once a week. Additionally, they have a five-hour block on Fridays with mandatory volunteer time and a mandatory one-hour library time. The second semester is spent with an on-sight practicum. The goal of the PATHS program is for participants to earn a certificate in Direct Support Professional (i.e., working with people with disabilities) or Child Care Professional (*PATHS Certificate Program*, n.d.). The two certification groups take the majority of the classes separately, although there are two classes in which they are combined. To be eligible for the study, participants had to be over 18 years old and enrolled in the program. All participants live independently, on and off-campus with complete freedoms. Additionally, to be admitted into the program, applicants must be their own legal guardians.

Data was collected in January 2020. Through an email, participants were provided a *Qualtrics* link so that they could complete the survey online. Through the use of an online survey system, individuals could take all of the time they needed and use assistive devices to read and understand the survey. There was no compensation for completing the study as that could have been coercive. Once the participant opened the *Qualtrics* link, they were provided with the informed consent document that included the study purpose, risk, benefits, and the ability to withdraw at any time. They then had to provide informed consent by clicking the button that they agreed to participate. The study was approved by the Institutional Review Board prior to data collection. Fourteen participants provided sociometric data (66.7%) and seventeen provided demographic data (80.9%). Typically in network analyses, at least a 60% response rate is needed to represent the overall network accurately (Cillessen & Marks, 2011).

## Measures

Participants were asked to provide demographic, mental health, and network data via an online survey. Demographic variables included name, gender, sexuality, diagnosis, and age. Names were needed so that whole network connections could be created. Gender options were male, female, or other. Sexuality included the options of straight, gay/lesbian, bisexual, pansexual, or an open-ended “other.” Diagnosis was an open-ended question that allowed participants to list all intellectual, physical, and mental health diagnosis they had received.

**Depression.** Depression was calculated from the eight-item version of the Personal Health Questionnaire (PHQ-8; Kroenke et al., 2009). The PHQ-8, is a modified version of the PHQ-9 but removes the suicidality and personal harm question. The PHQ-8 uses a 4-point Likert scale (0=not at all, 3=nearly every day). A total PHQ score was created by summing all items. The higher the score, the more severe depression. A score of 10 or greater indicates major depression and a score of 20 or above indicates severe major depression. Our sample data yielded a Cronbach’s alpha of 0.60.

There is a final question, outside of the standard eight, that asks “with these problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?” This question attempts to assess the impact of individual depression on daily living. The answer choices are on a 4-point Likert scale ranging from 1 meaning not difficult at all to 4 meaning extremely difficult. The result of this question is not included in the sum score.

**Sociometric networks**. Participants answered four questions to assess three different types of support and trust within a whole network. These questions were meant to gauge appraisal, belonging, and tangible support and trust. The questions to collect whole network data were: "if you needed to talk to someone about issues in your life (e.g., family, friends, work), who in the PATHS program would you go to?", "if you wanted to do a fun activity (e.g., go to the movies, shop, watch a sport), who in the PATHS program would you go do the activity with?", "if you needed money or a place to live, who in the PATHS program would you ask?" , and "Who in the PATHS program do you trust?"  Trust was included as a separate network because it can be seen as a precursor to all types of support. Although trust is not necessary for support to be provided, trust always plays a critical role in the activation (Tang et al., 2013). Trust was included to potentially differentiate properties associated with the construct compared to the three types of support.

In order to properly understand the whole network, several network characteristics need to be measured. These characteristics are broken up into node-level and network-level variables. All network variables that were assessed can be found in *Table 9* along with definitions of the variables.

*Centrality* is a node's position in a network and acts as an umbrella term for a myriad of measures (Borgatti et al., 2013; Wasserman & Faust, 1994). Centrality denotes structural importance. Popular measures of centrality include degree (i.e., total number of ties), closeness (i.e., extent to which a node is close to all other nodes), betweenness (i.e., who is on a the shortest pathway between two nodes the most, network controllers), and eigenvector (i.e., being connected to well-connected nodes). Different centrality measures can be linked to different support provided and individual well-being. *Cohesion* is a group measure (e.g. transitivity, reciprocity, clustering coefficient) that identifies how the whole network is connected and if there are subgroups that have formed (Borgatti et al., 2013; Valente, 2010). Cohesion can be analyzed based off shared behaviors because research indicates that people are more likely to associate with those who partake in similar behaviors or share an attribute (Valente, 2010). Cohesion could be an important factor when observing quality of life or types of diagnosis within people who experience IDD. Finally, structural, network-level measures could provide insight into the effectiveness of the program in bringing people together. These measures look at the network as a whole, instead of characteristics of the nodes themselves. Some network-level measures include overall size, density (total network connection), reciprocity (i.e., uni- or bi-directional relationships), isolates, core-periphery, and structural holes (Borgatti et al., 2013; Valente, 2010).

Complete network data was collected through a rostered format. Participants were prompted through a whole network support question from above (e.g., if you needed money or a place to live, who in the PATHS program would you ask?) and provided a roster that included names of everyone in the PATHS program in order to select all names that provided that type of support. There was no nomination limit, meaning participants could check as many names under each prompt as was applicable to them.

**Analysis**

Social network analysis does not assume independence between units of analysis because it relies on the assumption that nodes are interdependent (Borgatti et al., 2013). Due to this, permutation tests must be conducted to account for interdependence in the data. Quadratic assignment procedures (QAP) are a form of permutation tests that analyze bivariate correlations between two or more shared variables amongst a set of nodes (i.e., matrices) instead of on individual variables.

In order to run a QAP correlation, adjacency matrices are created for each variable of interest. Individual variables are transformed into a square matrix based on similarities or differences between nodes. *Figures 2-4* provide examples of how adjacency matrices are created with both similar or different calculations utilizing the examples of diagnosis and PHQ-8 sum scores (Patterson et al., 2020). If matrices are created based on similarities, and they share the same characteristic, like gender or diagnosis, then they receive a “1” in the shared cell. If they differ in that characteristic, then their intersections on the matrix would receive a zero, as seen in *Figure 3*. When matrices are created based on differences, the individual’s score in the top row is subtracted from the individual’s score in the first column, as seen in *Figure 4*. In this study, gender, sexuality, diagnosis, and those in the core were converted to matrices based on similarities; whereas, PHQ-8 sums, PHQ-8 impact of daily living question, eigenvector centrality, in-degree centrality, out-degree centrality, betweenness centrality, in-degree closeness, out-degree closeness, closeness centrality, and clustering coefficient were converted to matrices based on absolute differences.

Descriptive statistics were calculated using SPSS for demographic variables (i.e., age, diagnosis, sum scores). Network variables, adjacency matrices, and QAP correlations were calculated and conducted in UCINET (Borgatti et al., 2002). To conduct a QAP correlation, with the purpose to test associations between networks, the newly created adjacency matrices are correlated, resulting in a new correlation (observed) matrix and each cell is given a Pearson's r correlation value. UCINET then randomly permutes rows and columns of each matrix to create new matrices that are correlated to the created observed matrix. This step occurs thousands of times and creates a QAP effect size (similar to a Pearson's r correlation value) and a p-value (Borgatti et al., 2013). QAP correlations were conducted for each of the three types of support and trust across all variables. Network visualization graphs were created using NETDRAW (Borgatti, 2002).

## Results

### Descriptive Statistics

The open-ended diagnosis data were coded into no diagnosis or unknown, Attention Deficit Disorder (ADD), Autism, and unspecified intellectual disability. Most participants were diagnosed with a non-specified intellectual disability (33.3%), followed by no or an unknown disability (19%), Autism (14.3%), and ADD (4.8%). The average age of participants was 20.4 years (SD=1.96) and most (76.2%) were females. The majority of participants (66.7%; n=14) scored normally on the PHQ-8; whereas, 4 participants (19%) were categorized as having moderate depression. All sample characteristics can be found in *Table 10.*

Between the four sociometric networks, the average density was .126, with an average of 55 ties (SD=15.35). The average degree for nodes were 2.512 (SD=.934), with an overall centralization index of 0.455. There was an average of 2.5 isolates (SD=1.73) and almost a quarter (23.6%) of ties were reciprocal. The average clustering coefficient was .331. *Table 9* provides complete definitions and descriptive statistics of node-level and network-level measures. *Table 11* provides the node-level and network-level statistics for each individual type of support.

## QAP Correlations

To determine if certain network positions or patterns were associated with depression among PATHS participants, QAP correlations were conducted between PHQ-8 sum scores, attribute variables (diagnosis, gender, sexuality, impacts of daily living), and network variables. QAP correlation analysis revealed that PHQ-8 scores were statistically significantly associated with shared sexuality (QAP r=-.544) and betweenness centrality for tangible support and trust (QAP r=-.195 and -.183). Betweenness centrality is indicative of who is on the geodesic, or shortest path between two nodes—which means they have the potential to be network controllers or secondary supporters. *Tables 12-16* depict all QAP correlations between PHQ-8 sum scores and demographic and network variables for the three types of support and trust.

## Multiple Regression QAP Analysis

Network variables (betweenness centrality, clustering coefficient, closeness centrality, eigenvector centrality, in-closeness, out-closeness, in-degree, and out-degree) and attribute variables (diagnosis, gender, sexuality, and impact on daily living) were regressed on PHQ-8 sum score for each of the three types of support (appraisal, belonging, and tangible) and trust. PHQ-8 sum was converted into a square matrix by finding differences between node scores. All MR-QAP analysis resulted in statistically significant models, explaining between 34.3% and 93.1% of the variance in PHQ-8 scores for each of the four supports. Diagnosis was the only statistically significant variable across all models.

**Appraisal support.** When combined together, attribute and network variables accounted for 34.3% of the variance in PHQ-8 sum score. According to the MR- QAP analysis, depression score was related most with sexuality (standardized coefficient= -.510, p=.013) and diagnosis (standardized coefficient= -.204, p=.050). The other variables were not significant predictors of the model. See *Table 17* for the full regression model explaining appraisal support. *Figure 5* provides a visualization of the network.

**Belonging support.** Attribute and network variables accounted for 77.1% of the variance in PHQ-8 sum scores in the belonging support network. Depression score was most related to out-closeness (standardized coefficient= .705, p=.001) and betweenness centrality (standardized coefficient= -.613, p=.001). In-closeness (standardized coefficient= .459, p=.002), gender (standardized coefficient= .380, p=.003), out-degree (standardized coefficient= -.310, p=.042), and diagnosis (standardized coefficient= -.289, p=.004) were also statistically significantly related to PHQ-8 sum scores. All other variables were not significant predictors of the model. See *Table 18* for the full regression model of belonging support. *Figure 6* provides a visualization of the network.

**Tangible support.** When combined together, attribute and network variables for tangible support accounted for 93.1% of the variance in PHQ-8 sum score. Sum score was most related to clustering coefficient (standardized coefficient= -2.090, p=.032) and out-closeness (standardized coefficient= 2.120, p=.017). The other statistically significant predictors included sexuality (standardized coefficient= -.822, p=.002), diagnosis (standardized coefficient= -.492, p=.005), and eigenvector centrality (standardized coefficient= -.456, p= .045). No other variables were statistically significant predictors of the model. See *Table 19* for the full regression model of tangible support. *Figure 7* provides a visualization of the network.

**Trust.** Attribute and network variables for trust accounted for 66.7% of the variance in PHQ-8 sum score. Depression score was most related to in-closeness (standardized coefficient= .713, p=.001) and diagnosis (standardized coefficient= -.408, p=.004). The other statistically significant predictors included in-degree (standardized coefficient= -.370, p=.019), gender (standardized coefficient= .265, p=.025), and sexuality (standardized coefficient= -.230, p= .040). No other variables were statistically significant predictors of the model. See *Table 20* for the full regression model of trust. *Figure 8* provides a visualization of the network.

# Discussion

The purpose of this study was to use sociometric SNA to investigate whether network variables were associated with depression and social support among a group of adults who experience IDD. Results suggest distinct network variables were associated with different types of support and the same diagnosis is the one variable that is shared across all models.

## Appraisal Support

Shared sexuality and a shared diagnosis were both negatively associated with PHQ-8 score. This means that as individuals connect with others who share the same diagnoses and sexuality, they report lower depression scores. This aligns with the network theory concept of *homophily*. Homophily posits that people tend to connect with others who are like them in some way (McPherson et al., 2001). Further, homophily is often associated with health behaviors and outcomes, including risky behaviors like drugs (Rai et al., 2003), smoking (Alexander et al., 2001; Urberg et al., 1997), and being overweight (Valente et al., 2009). For example, in Bollen and colleagues' (2011) study on the general population, participants who had similar general well-being scores and overall happiness scores on social media tended to interact more often. This indicates that those with similar demeanors and outlook on life clump together and find each other on social media but also are more likely to interact. In sum, a person's network is typically a reflection of them because people often feel more comfortable, and as a result connect with, others who have shared experiences or characteristics (Valente, 2010). However, when needing advice or evaluation on life events, possessing shared characteristics is even more important. For appraisal support, the feelings of being understood because two people share the same attributes, can increase the perception of advice credibility and emotional safety because there is a sense of understanding (Wright, 2000).

### Belonging Support

Out-closeness was positively associated with PHQ-8 scores, indicating the more easily a node could reach others in the network, the lower their depression scores. Conversely, the more removed a node is from others (resulting in other nodes being less "reachable" to the ego), the higher PHQ-8 scores tended to be. Closeness centrality reflects the distance a node is from all other nodes in the network (Sabidussi, 1966; Wasserman & Faust, 1994). Out-closeness indicates a node is "closer" and therefore able to more easily reach others in the network, while in-closeness measures how reachable a particular node is to the rest of the network (Borgatti et al., 2013). Literature indicates that loneliness and isolation, particularly for those with IDD, is linked to higher depression scores (Margalit, 2004; Stancliffe et al., 2007). Given those with IDD are more likely to be isolated compared to their neurotypical peers (Margalit, 2004; Sheppard-Jones et al., 2005), and isolation is often associated with depression (House et al., 1988; Stancliffe et al., 2007), the relationship between closeness and depression was unsurprising. Unfortunately, this methodology does not allow for the understanding of other networks that a node is a part of. Just because a node is less close in this network does not mean they are not highly connected or embedded within another network. Participants may feel like they receive belong support elsewhere, and not within the program. An egocentric network analysis would allow for the investigation of sources of support within an outside of the defined group and should be further explored.

In addition to closeness, betweenness scores were also related to PHQ-8 within the belonging support network. Betweenness centrality means that nodes with higher scores are more likely to be an intermediary between two other people in the network and can bridge different groups of people in the network. Additionally, nodes with high betweenness scores are typically the network controllers, in that information, attitudes, and even behaviors often have to "pass through" them in order to reach the rest of the network (Wasserman & Faust, 1994). This finding is indicative that individuals with higher betweenness scores have greater access to various pockets in the network. Through this, they will likely benefit from support from multiple formal and informal groups within the network. Previous literature has shown that those who give support experience equal to or more emotional health benefits compared to receiving support (Brown et al., 2003; Thomas, 2010). If nodes are connected to many pockets of people, not only are they potentially providing support to others, which is a benefit, but receiving it as well.

## Tangible Support

Tangible support networks within this group were the smallest and least connected of the support networks. This finding is validated through network-level variables average degree, density, and isolates. A low average degree means there were fewer nominations (sent and received) across all nodes. Density is calculated by dividing total observed ties by total potential ties (Borgatti et al., 2013). A low number indicates a sparser network, with few of the possible ties in the network observed. Isolates are the nodes that do not have any ties (Borgatti et al., 2013). The summation of these findings when compared to the other networks suggests that individuals with IDD are unlikely to provide tangible support to each other in this network. Those with IDD tend to be resource poor (i.e., they do not have access to resources to provide; Perkins & Haley, 2013) and thus, unlikely to be a source of tangible resources such as money or a service like driving. They have also grown up utilizing other networks (e.g., family) for tangible support so it may be intuitive to reach out to family, instead of a peer (Bengtson, 2001).

Eigenvector centrality was negatively associated with PHQ-8 scores in the tangible support network, meaning as eigenvector centrality increased, depression scores decreased. Eigenvector centrality is defined as being closely connected to well-connected/powerful people (Borgatti et al., 2013; Valente, 2010). Those with higher eigenvector centrality scores may not be the most popular person, but they are connected to the most influential nodes. Those with high eigenvector centrality have better access to resources, diffusion of information, and potential impact on what happens in the network if the people that they are tied to have access to those resources (Borgatti et al., 2013; Wasserman & Faust, 1994). Those with the ability to activate tangible support and resources can decrease stress and depression because major life stressors can be solved with resources like food, money, and transportation (Coffman, 2008; Hirschman & Bourjolly, 2005; Perkins & Haley, 2013; van Praag, 2004).

## Trust

The PATHs program facilitated a trusting network. Across the four models, trust was the most connected, registering the highest density, highest total number of ties, and resulting in only one isolate. Trust is a precursor to all types of support measured in this study. There may be varying levels of trust needed to activate different support networks, trust always plays a critical role in the activation (Tang et al., 2013). Similar to belonging support, diagnosis and sexuality were negatively associated with PHQ-8 scores within the trust network. If ties had the same diagnosis or sexuality, their PHQ-8 scores were better (i.e., they had fewer depressive tendencies). This indicates finding security with others who have similar life experiences allows for trusting relationships to form (Winter & Kataria, 2013). Similar findings have occurred for deviants and friendship networks (Flashman & Gambetta, 2014; Winter & Kataria, 2013). Deviants found homophilic trust because the actions of their trusted relations were "blackmailable" (Flashman & Gambetta, 2014). They trust each other because there is an unspoken bond knowing they have knowledge about the other person that is not socially acceptable. This is like negative social norms around sexuality and having a diagnosed disability (Johnson & Traustadóttir, 2005). There could be a similar exchange occurring with trust and information about another person who is different in societal standards.

While diagnosis and sexuality homophily has a positive impact on depression, gender does not. The sample was overwhelmingly female, suggesting that females may not trust other females the way that they do men. Literature has found that women prefer to socialize with other women but do not trust them (Bevelander & Page, 2011). If programs are wanting to build trust among participants, then programs need to be created with representatives across all genders, sexualities, and diagnoses.

### Limitations

Findings of this study are not generalizable because all networks are unique, meaning that replication with the same or a similar group of people could yield different results (Valente, 2010). To obtain more conclusive and generalizable findings, this study would need to be conducted multiple times with similar networks and within comparable settings. Even this network could produce different findings over time because relationships are temporal and always changing (Valente, 2010). Another limitation is there was not true census data. Because response rate was less than 100% and the addition or removal of a single node or tie can change the entire structure, the network could not be fully conceptualized (Valente, 2010). Additionally, isolates and centrality measures are impacted by missing data, and are likely to adjust with a full representation of the network.

## Conclusion

Shared life experiences among individuals with IDD, like diagnosis and sexuality, are important in the seeking out of appraisal and belonging support, along with trust, in a network of adults with IDD. Tangible support was not often provided to peers with IDD and most likely to come from family and other instrumental supports. Findings from this study can inform future career preparation programs that are developed and for organizations that work with people with IDD.  If network characteristics that foster success (e.g., eigenvector centrality) and decrease mental health can be understood, programs could be developed around significant network properties and capitalize on certain positions within the network.

*Table 9*. Definitions and descriptive statistics of network measures

| | **Definition** | **Mean or Network Score** | **SD** |
|---|---|---|---|
| | **Node Level** | | |
| Degree Centrality | Total number of ties—both in and out; typically, a measure of power, prestige, or popularity | 5.488 | 3.427 |
| In-Degree | The number of nominations coming into a node. | 2.976 | .218 |
| Out-Degree | The number of nominations a node provides. | 2.512 | 3.431 |
| Closeness Centrality | The extent to which a node is close with all other nodes; the higher the score, the less close a node is and more difficult to reach. | 50.976 | 19.994 |
| In-Closeness | A measure to indicate how close nodes are to the center of the network; a higher score shows a node is more in the periphery; measured on directional, in ties. | 83.833 | 14.465 |
| Out-Closeness | Nodes with higher score are further from core nodes; measured on directional, out ties. | 83.821 | 28.329 |
| Betweenness Centrality | Nodes with higher scores are on more geodesic (direct) paths between two other nodes; these are typically the network controllers. | 9.107 | 14.764 |
| Eigenvector Centrality | Measure of being connected to well-connected nodes or the connected to powerful people | .309 | .263 |
| Node Clustering Coefficient | The clique-ness of a network and if ties are connected to each other. | .324 | .227 |
| | **Network Level** | | |
| Total Ties | The total number of nominations between all nodes | 55.5 | 15.35 |
| Average Degree | Average degree in a graph; found by dividing in-degree by out-degree | 2.512 | .934 |
| Centralization Index | A measure of network structure; indicates the distribution of power across a network or how hierarchical a network is. | .455 | .109 |
| Density | The total number of ties divided by the total number of possible ties; indicator of the interconnectedness of the network. | .126 | .046 |
| Average Distance | Average geodesic (smallest) pathway to get between two nodes. | 2.078 | .150 |
| Core Correlation | Fit statistic of those in the core and periphery. | .570 | .135 |

*Table 9* Continued.

| | **Definition** | **Mean or Network Score** | **SD** |
|---|---|---|---|
| Clustering Coefficient | Mean clustering coefficient of all nodes. | .331 | .119 |
| Reciprocity | The proportion of arcs (edges) that are reciprocated. | .236 | .155 |
| Transitivity | The number of triples that are transitive divided by the number of paths with a length of 2. | .464 | .122 |
| Isolates | The number of nodes not connected to any other nodes | 2.5 | 1.73 |

*Table 10*. Sample characteristics of 21 individuals involved in career preparation program

| Variable | N | % | M | SD |
|---|---|---|---|---|
| Age | | | 20.4 | 1.96 |
| Females | 16 | 76.2 | | |
| Sexuality | | | | |
| Straight | 14 | 66.7 | | |
| Gay/Lesbian | 1 | 4.8 | | |
| Bisexual | 1 | 4.8 | | |
| Other | 1 | 4.8 | | |
| Diagnosis | | | | |
| None/Unknown | 4 | 19.0 | | |
| ADD | 1 | 4.8 | | |
| Autism | 3 | 14.3 | | |
| Non-specified intellectual | 7 | 33.3 | | |
| Depression | | | 7.06 | 1.94 |
| Normal (0-9) | 13 | 61.9 | | |
| Moderate (10-19) | 4 | 19.0 | | |
| Severe (20+) | 0 | 0 | | |
| Daily difficulty from depression | | | | |
| Not difficult at all | 4 | 19.0 | | |
| Somewhat difficult | 9 | 42.9 | | |
| Very difficult | 3 | 14.3 | | |

*Table 11*. Descriptive statistics of network measures for each type of support

| | Appraisal | Belonging | Tangible | Trust |
|---|---|---|---|---|
| **Node Level** | | | | |
| Degree Centrality | 5.857 (2.954) | 5.429 (3.115) | 4.190 (2.228) | 6.476 (4.708) |
| In-Degree | 2.95 (.224) | 2.95 (.224) | 2.95 (.224) | 3.05 (.224) |
| Out-Degree | 3.05 (3.050) | 2.6 (3.315) | 1.3 (2.227) | 3.6 (4.661) |
| Closeness Centrality | 38.3 (5.497) | 56 (22.964) | 70.05 (18.704) | 40.4 (10.840) |
| In-Closeness | 91 (17.137) | 78.1 (13.699) | 91.2 (8.953) | 77.95 (10.89) |
| Out-Closeness | 86.789 (31.793) | 77.286 (21.211) | 90.1 (14.153) | 75.35 (38.416) |
| Betweenness Centrality | 13.9 (17.143) | 8.818 (13.508) | 3.1 (6.707) | 12.35 (18.481) |
| Eigenvector Centrality | .197 (.089) | .366 (.287) | .283 (.271) | .423 (.317) |
| Node Clustering Coefficient | .188 (.128) | .339 (.222) | .331 (.172) | .469 (.272) |
| **Network Level** | | | | |
| Total Ties | 62 | 52 | 26 | 72 |
| Average Degree | 2.905 | 2.476 | 1.238 | 3.429 |
| Centralization Index | .447 | ,471 | .318 | .584 |
| Density | .145 | .124 | .062 | .171 |
| Average Distance | 2.287 | 1.987 | 1.954 | 2.083 |
| Core Correlation | .390 | .599 | .580 | .718 |
| Clustering Coefficient | .179 | .349 | .328 | .469 |
| Reciprocity | .131 | .346 | .077 | .389 |
| Transitivity | .607 | .415 | .324 | .510 |
| Isolates | 2 | 2 | 5 | 1 |

*Table 12.* QAP correlations on demographic variables amongst a group of individuals with intellectual and developmental disabilities

| Variable | Diagnosis | Gender | Sexuality | Daily Living | PHQ-8 Sum |
|---|---|---|---|---|---|
| Diagnosis | - | | | | |
| Gender | .226* | - | | | |
| Sexuality | -.019 | .058 | - | | |
| Daily Living | .050 | -.147 | .253 | - | |
| PHQ-8 Sum | -.148 | .004 | -.544* | -.069 | - |

*Note.* * p<.05; ** p<.01

*Table 13*. QAP correlations on appraisal support amongst a group of individuals with intellectual and developmental disabilities

| Variable | PHQ Sum | Betweenness | Cluster Coefficient | Closeness Centrality | Eigenvector | In closeness | In degree | Out closeness |
|---|---|---|---|---|---|---|---|---|
| PHQ Sum | - | | | | | | | |
| Betweenness | -.047 | - | | | | | | |
| Cluster Coefficient | .046 | -.025 | - | | | | | |
| Closeness | -.108 | .117 | .209* | - | | | | |
| Eigenvector | -.088 | .119 | .291** | .848*** | - | | | |
| In closeness | -.147 | -.123 | .063 | .563** | .310* | - | | |
| In degree | -.095 | -.050 | .143 | .252 | .073 | .556*** | - | |
| Out closeness | -.089 | .373** | -.017 | .469*** | .483*** | .168* | -.069 | - |
| Out degree | -.093 | .273* | -.050 | .428*** | .480*** | .134 | -.123 | .823*** |

*Note*. * p<.05; ** p<.01; *** p<.001

*Table 14.* QAP correlation on belonging support amongst a group of individuals with intellectual and developmental disabilities

| Variable | PHQ Sum | Betweenness | Clustering Coefficient | Closeness | Eigenvector | In closeness | In degree | Out closeness |
|---|---|---|---|---|---|---|---|---|
| PHQ Sum | - | | | | | | | |
| Betweenness | -.161 | - | | | | | | |
| Cluster Coefficient | .155 | .162 | - | | | | | |
| Closeness | -.173 | -.004 | .564* | - | | | | |
| Eigenvector | -.113 | .593*** | -.001 | .145 | - | | | |
| In close | -.010 | .003 | .106 | .456*** | .059 | - | | |
| In degree | -.135 | -.088 | .010 | .356* | -.030 | .525*** | - | |
| Out close | .123 | .405** | .160 | .095 | .283** | .025 | -.067 | - |
| Out degree | -.134 | .719*** | .120 | -.014 | .389** | -.078 | .006 | .572*** |

*Note.* * p<.05; ** p<.01; *** p<.001

*Table 15.* QAP correlation on tangible support amongst a group of individuals with intellectual and developmental disabilities

| Variable | PHQ Sum | Betweenness | Cluster Coefficient | Closeness | Eigenvector | In closeness | In degree | Out closeness |
|---|---|---|---|---|---|---|---|---|
| PHQ Sum | - | | | | | | | |
| Betweenness | -.195** | - | | | | | | |
| Cluster Coefficient | -.021 | .211 | - | | | | | |
| Closeness | -.009 | .062 | .743*** | - | | | | |
| Eigenvector | .008 | -.074 | .157 | .275** | - | | | |
| In close | -.017 | .168* | .115 | .292*** | .001 | - | | |
| In degree | -.093 | .362* | .201 | .328*** | .020 | .636*** | - | |
| Out close | -.075 | .443** | .969*** | .171 | .335** | -.022 | .095 | - |
| Out degree | -.125 | .509* | .818*** | .109 | .383* | -.022 | -.016 | .814*** |

*Notes:* *= p<.05; **=p<.01; ***= p<.001

*Table 16.* QAP correlation on trust amongst a group of individuals with intellectual and developmental disabilities

| Variable | PHQ Sum | Betweenness | Cluster Coefficient | Closeness | Eigenvector | In closeness | In degree | Out closeness |
|---|---|---|---|---|---|---|---|---|
| PHQ Sum | - | | | | | | | |
| Betweenness | -.183* | - | | | | | | |
| Cluster Coefficient | -.018 | .197 | - | | | | | |
| Closeness | -.160 | .139 | .281 | - | | | | |
| Eigenvector | -.048 | .032 | -.034 | .032 | - | | | |
| In closeness | -.074 | -.099 | -.040 | .888** | .103 | - | | |
| In degree | -.058 | .092 | -.049 | .433*** | .039 | .513*** | - | |
| Out closeness | .111 | .383** | .526*** | .138** | .100 | .009 | .003 | - |
| Out degree | -.147 | .833*** | .346** | .154 | .135 | -.093 | -.060 | .532*** |

*Notes:* *= p<.05; **=p<.01; ***= p<.001

*Table 17*. MR-QAP regression on appraisal support amongst a group of individuals with intellectual and developmental disabilities

| $R^2$= .343, p=.012 | Standardized Coefficient | p-value |
|---|---|---|
| Intercept | 4.401 | |
| Diagnosis | -.204 | .050 |
| Gender | .065 | .373 |
| Sexuality | -.510 | .013 |
| Daily living | .100 | .228 |
| Betweenness | -.005 | .524 |
| Clustering coefficient | .088 | .262 |
| Closeness | -.183 | .286 |
| Eigenvector | .052 | .428 |
| In closeness | -.149 | .225 |
| In degree | .082 | .307 |
| Out closeness | .362 | .177 |
| Out degree | -.174 | .313 |

*Table 18.* MR-QAP regression on belonging support amongst a group of individuals with intellectual and developmental disabilities

| $R^2$= .771, p=.001 | Standardized Coefficient | p-value |
|---|---|---|
| Intercept | 4.608 | |
| Diagnosis | -.289 | .004 |
| Gender | .380 | .0025 |
| Sexuality | -.156 | .095 |
| Daily living | .004 | .482 |
| Betweenness | -.613 | .001 |
| Clustering coefficient | .133 | .121 |
| Closeness | -.189 | .098 |
| Eigenvector | -.029 | .400 |
| In closeness | .495 | .002 |
| In degree | -.132 | .061 |
| Out closeness | .705 | .001 |
| Out degree | .310 | .042 |

*Table 19.* MR-QAP regression on tangible support amongst a group of individuals with intellectual and developmental disabilities

| $R^2$= .931, p=.002 | Standardized Coefficient | p-value |
|---|---|---|
| Intercept | .301 | |
| Diagnosis | -.492 | .005 |
| Gender | -.561 | .152 |
| Sexuality | -.822 | .002 |
| Daily living | .045 | .290 |
| Betweenness | -.096 | .329 |
| Clustering coefficient | -2.090 | .032 |
| Closeness | -.034 | .430 |
| Eigenvector | -.456 | .045 |
| In closeness | -.348 | .302 |
| In degree | .087 | .273 |
| Out closeness | 2.120 | .017 |
| Out degree | .090 | .446 |

*Table 20.* MR-QAP regression on trust amongst a group of individuals with intellectual and developmental disabilities

| $R^2$= .667 p=.004 | Standardized Coefficient | p-value |
|---|---|---|
| Intercept | 8.890 | |
| Diagnosis | -.408 | .004 |
| Gender | .265 | .025 |
| Sexuality | -.230 | .040 |
| Daily living | .016 | .443 |
| Betweenness | .137 | .179 |
| Clustering coefficient | -.180 | .305 |
| Closeness | .016 | .432 |
| Eigenvector | -.090 | .211 |
| In closeness | .713 | .001 |
| In degree | -.370 | .019 |
| Out closeness | .275 | .145 |
| Out degree | -.073 | .405 |

*Figure 2*. Demographic variables reflecting diagnosis and PHQ-8 sum scores

| | Diagnosis | PHQ-8 Sum Score |
|---|---|---|
| Person 1 | 1 | 3 |
| Person 2 | 1 | 12 |
| Person 3 | 3 | 8 |

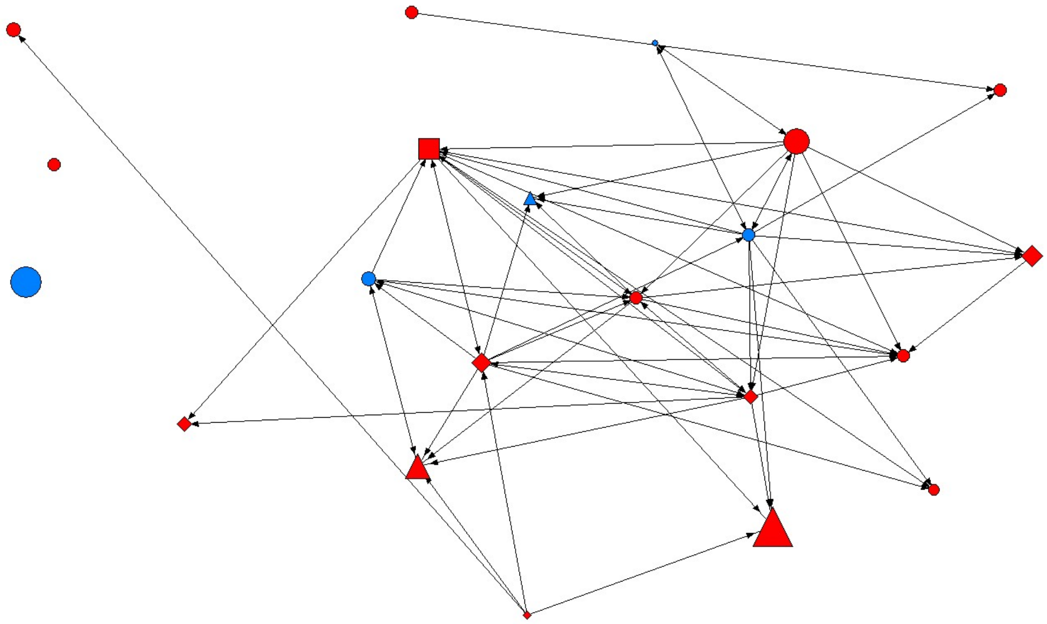
*Figure 3*. Adjacency matrix reflecting similarities between diagnoses

| | Person 1 | Person 2 | Person 3 |
|---|---|---|---|
| Person 1 | 1 | 1 | 0 |
| Person 2 | 1 | 1 | 0 |
| Person 3 | 0 | 0 | 1 |

*Figure 4.* Adjacency matrix reflecting differences between PHQ-8 sum scores

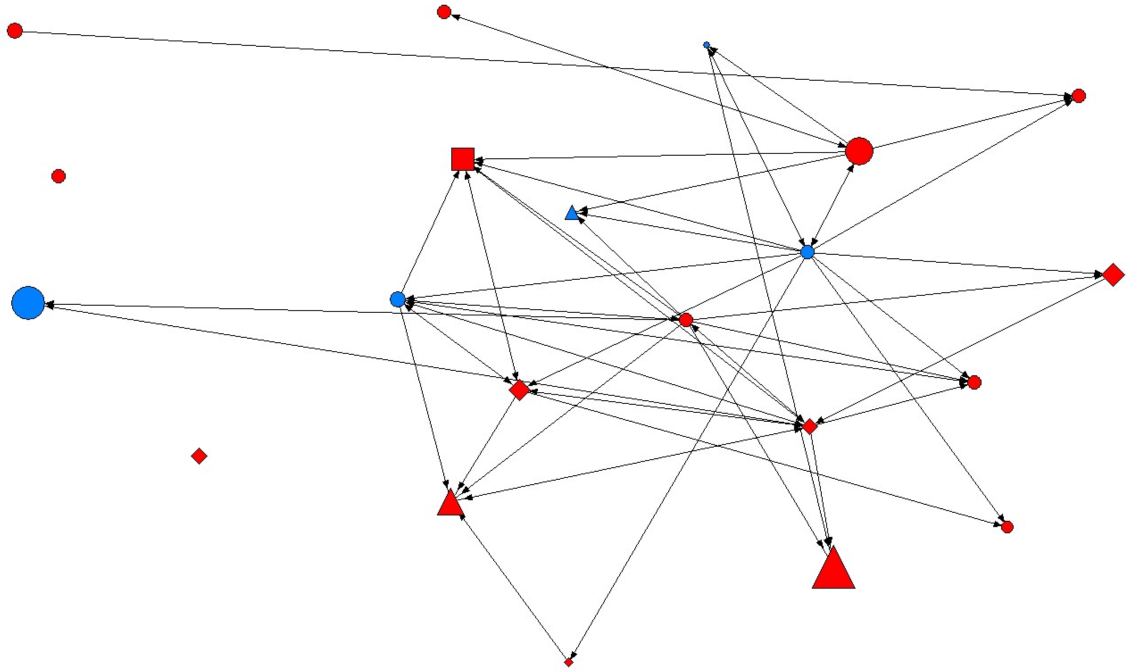
| | Person 1 | Person 2 | Person 3 |
|---|---|---|---|
| Person 1 | 0 | -9 | -5 |
| Person 2 | 9 | 0 | 4 |
| Person 3 | 5 | -4 | 0 |

*Figure 5*. Image of the appraisal support whole network



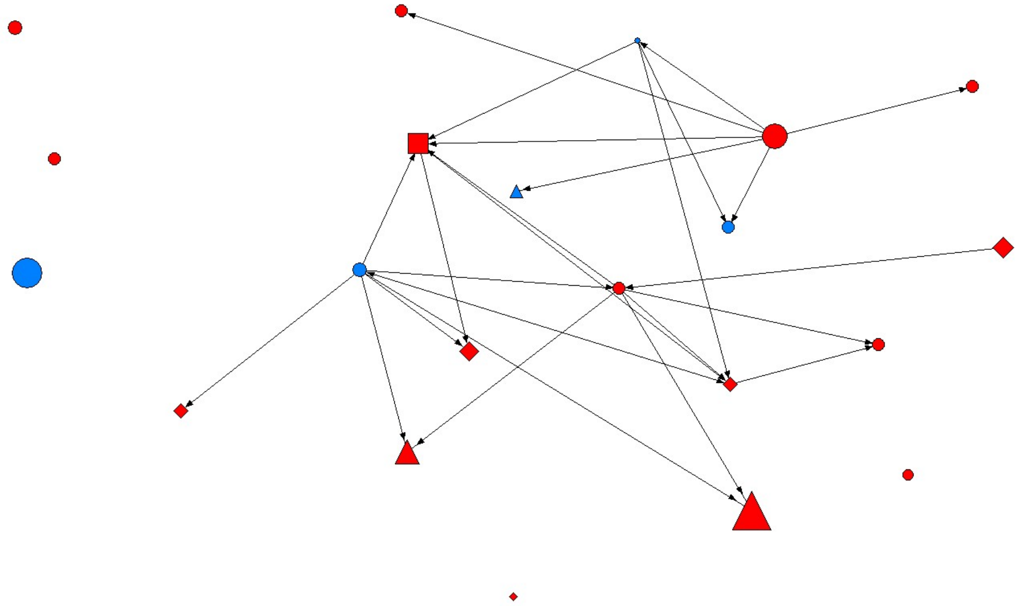
*Note:* Color denotes gender, females are red female and males are blue; Size denotes PHQ-8 sum score with the larger the node, the higher the score; Shape denotes diagnosis with circle meaning none or unknown diagnosis, square meaning Attention Deficit Disorder, triangle meaning Autism Spectrum Disorder, and diamond being an unspecified intellectual disability

*Figure 6.* Image of the belonging support whole network



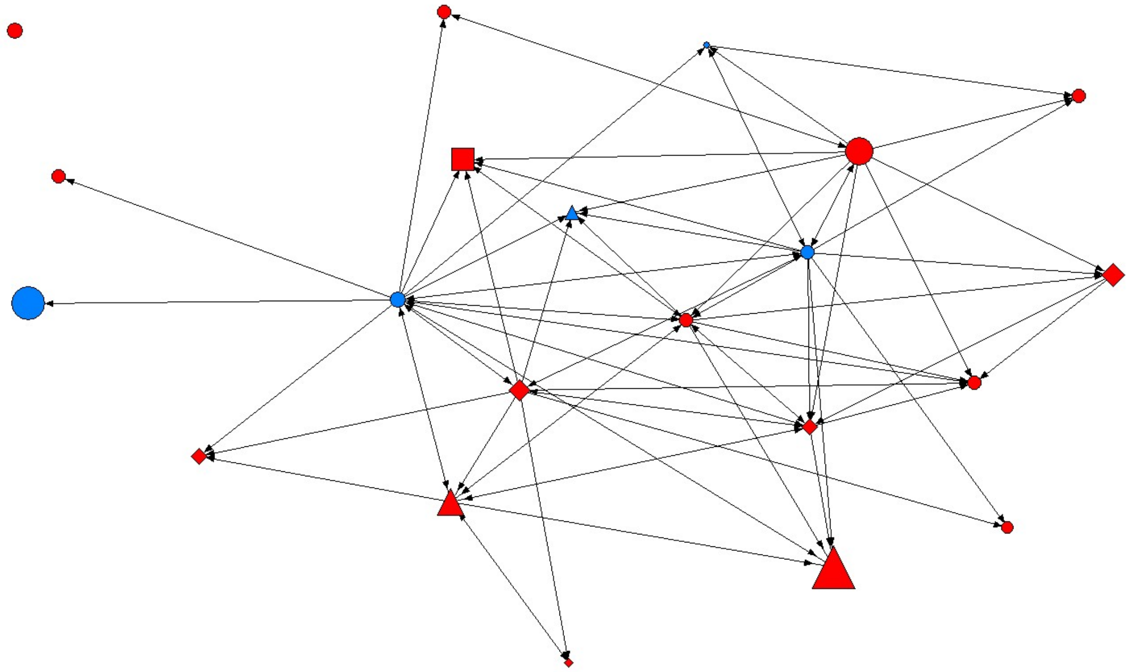
*Note:* Color denotes gender, females are red female and males are blue; Size denotes PHQ-8 sum score with the larger the node, the higher the score; Shape denotes diagnosis with circle meaning none or unknown diagnosis, square meaning Attention Deficit Disorder, triangle meaning Autism Spectrum Disorder, and diamond being an unspecified intellectual disability

*Figure 7*. Image of the tangible support whole network



*Note:* Color denotes gender, females are red female and males are blue; Size denotes PHQ-8 sum score with the larger the node, the higher the score; Shape denotes diagnosis with circle meaning none or unknown diagnosis, square meaning Attention Deficit Disorder, triangle meaning Autism Spectrum Disorder, and diamond being an unspecified intellectual disability

*Figure 8.* Image of the trust whole network



*Note:* Color denotes gender, females are red female and males are blue; Size denotes PHQ-8 sum score with the larger the node, the higher the score; Shape denotes diagnosis with circle meaning none or unknown diagnosis, square meaning Attention Deficit Disorder, triangle meaning Autism Spectrum Disorder, and diamond being an unspecified intellectual disability

# CHAPTER V

# CONCLUSION

The purpose of this dissertation was to explore egocentric and sociometric networks of social support among a sample of young adults with intellectual and developmental disabilities (IDD) who attend a career preparation program at a large, southern university in the United States. In order to achieve the purpose, three independent articles were written: 1) a scoping literature review about the social networks of those with IDD (Chapter II), 2) an egocentric network analysis regarding social support provision from various members of personal networks for a group of young adults who experience IDD (Chapter III), and 3) a sociometric network analysis to understand social support provision from participants in a career preparation program with group of young adults who experience IDD (Chapter IV).

## Chapter Findings and Results

### Chapter II: Scoping Literature Review

A scoping literature review was conducted to examine how the social networks for those with IDD have been assessed and conceptualized, along with understanding the composition of their networks. Between October 2019 and March 2020, Medine, Ebsco Cinahl, and PsychInfo were searched regarding disabilities and social networks. The Cochrane Collaboration standard was used to guide the search (Higgins et al., 2019). Inclusion criteria included articles that evaluated the networks of individuals who had disabilities, took place in the United States, and collected data directly from the individuals. Exclusion included articles written in a language other than English, non-peer review articles, studies outside of the United States, and studies that collected data from someone other than the individual (i.e., parents, caregivers). Initially, 408 articles were identified through the search. Seven full-text articles were reviewed.

The scoping literature review resulted in three major findings across the seven studies. The first finding was discrepancies in study methods, including who was sampled and study design. A majority of the programs (57%) collected data from children (Coleman & Minnett, 1993; Cosbey et al., 2010; Cunningham et al., 2009; Hoyle & Serafica, 1988). The other three studied young adults transitioning from high school (Barone et al., 1993) and adults (Ouellette et al., 1994; Ward et al., 2013). Additionally, data collection methods differed across the studies with half using across-sectional design, two used a pretest/posttest design, and the last was a time series design. Further, all seven used differing methods to elicit names of people in an individual's network. No two studies in the review were alike, indicating that replication has not occurred and comparisons across findings is not possible. The replication of studies is necessary to draw conclusions across differing populations and settings.

The second finding was inconsistency in network composition for people with IDD, or attributes of the individuals who make up support networks. One study indicates that people with IDD do not have friendship networks (Cunningham et al., 2009); another, found that others say that adding friends to a network is possible (Ouellette et al., 1994). A third study suggested that social status, not disability, impacts peer relationships for children. For those who live in care facilities, their networks are mainly made up of formal, paid relationships (Ouellette et al., 1994). This outcome could be rationalized by realizing that those in full-time care facilities interact mainly with formal relationships and those relationships are who they depend on for support. When comparing them to children who live at home and are in school, children at home had networks frequently comprised of family members and are not as diverse (Cosbey et al., 2010). Outcomes from this theme indicate that network study findings should be contextualized within the population and setting.

The third major finding from our review was that networks for people with IDD can grow. This contradicts previous beliefs that networks do not grow in size for those with IDD (Forrester-Jones et al., 2006). Ward and colleagues (2013), along with Ouellette, Homer, and Newton (1994) provided justification that when provided intentional activities or programs—no matter the age— social networks have the opportunity to grow and that peers, specifically others with disabilities. And while Barone and colleagues (1993) found that while networks decreased when high school students transitioned out of the school setting, like in finding two, context matters. In programs where the intention is to create networks, networks have the capacity to grow.

This chapter established the need and support for further investigating the networks of people with disabilities using a social network analysis approach. The transitional age from high school into adulthood seems to be a critical age in which to provide programs that intentionally bring together those with IDD. The transitional age is when individuals are losing social supports from their current educational system but also becoming independent. Not only would a study that observed network changes with this population be similar to Ward and colleagues (2013), but bringing individuals with IDD together allows for them to explore, create, and grow their own networks, while also providing mental health benefits (Brim, 1974; Clara et al., 2003; Cohen & McKay, 1984; Weber et al., 2010).

Chapters III and IV were network studies using the same sample— 21 young adults with IDD who enroll in a career preparation program (Postsecondary Access and Training in Human Services; PATHS) at a large, public university in the southern United States. The goal of both studies was to understand the composition and structure of social support networks using two different types of social network analysis. Survey responses were collected from participants in December 2019 and January 2020 and included demographic variables, attribute variables, and network variables. Egocentric network data was collected at both time points, while sociometric data was only collected in January.

## Chapter III: Egocentric Network Analysis

The aim of Chapter III was to understand 1) what compositional patterns exist in support networks for adults with IDD who enroll in a career preparation program; 2) do the egocentric networks of adults who participate change over time; and 3) are there differences in network properties across three different types of support (i.e., do adults in the program tend to nominate the same people for all three types of support?). We conducted descriptive statistics regarding the demographics and network ties across three types of support (i.e., belonging, appraisal, tangible). Results indicated there were observed differences in attribute composition for the type of support being provided and slight differences across time.

For belonging support, friends were the main types of nominations and the majority were from the PATHS program. There was also very little change between the two time points, even while participants were away for break. These outcomes contradict the previous research that states those with IDD have networks mainly comprised of family and formal relationships and are unstable (Cunningham et al., 2009; Kennedy et al., 1989; Krauss et al., 1992; Sheppard-Jones et al., 2005). Networks for appraisal support were almost split between friends and family. Formal relationships were also the most prevalent in appraisal support, compared to the other types, but did not make up a large percentage of the networks. Additionally, although the composition of networks stayed consistent with friends, there was a decrease in the percentage of PATHS participants nominated at the second time point for appraisal support. This demonstrates that appraisal support relationships formed with other participants may not be as stable when not in the same geographic space. Family support played the largest role in tangible support. Previous literature suggests that familial ties are key providers of tangible support for all people (Coffman, 2008; Hirschman & Bourjolly, 2005). Other PATHS participants were mainly nominated when asked who the participant would go to if they needed a ride. The findings for this study are indicative of network composition differences when parsing out type of support.

## Chapter IV: Sociometric Network Analysis

Chapter IV used sociometric network analysis to understand the support provided and received within a group of young adults in the PATHS program. The same sample of program participants as Chapter III and data was collected at the second time point. Support provision was bound by those in the same career preparation program and participants were provided a roster to build their networks (Chapter IV). Three types of social support were assessed in both studies—appraisal, belonging, and tangible—additionally, trust within the network was measured.

The aim of Chapter IV was to answer the questions 1) how effective was PATHS in creating social support relationships amongst participants and 2) were certain positions or patterns within the whole network associated with depression? In the whole network study, we conducted four MR-QAP analyses (multiple regression quadratic assignment procedure) predicting depressive symptoms across each of the three types of support (i.e., appraisal, belonging, tangible) and trust. MR-QAP analysis account for non-independence in network data. Adjacency matrices are created for each variable of interest so that analyses are computed on the dyads between each node, based on similarities or differences, instead of the individual. Each regression model included demographic information, attribute variables, and node-level characteristics. Node-level characteristics are measurements pertaining to an individual's, or node's, position within the network compared to the other nodes. An example is centrality, or the prestige within a network (Valente, 2010).

Results from the study suggest different network variables were associated with depression and different types of support among a group of young adults who experience IDD. A shared diagnosis is the one variable that is statistically significant across all models and was associated with decreased depression scores for the three types of support and trust. For appraisal support, a shared sexuality and shared diagnosis were both negatively associated with PHQ-8 score, meaning depression scores tended to be lower between ties of the same sexuality and diagnosis. Network specific variables (e.g., degree centrality, betweenness) were not associated with PHQ-8 scores. For belonging support, depression score was most related to the network variables of out-closeness (i.e., being further away from central nodes) and betweenness centrality (i.e., being on the shortest path that connects two nodes the most often). In the tangible support model, depression was most related to the network variables of clustering coefficient (i.e., being in cliques with other ties) and out-closeness. For trust, depression was most linked to the network variable of in-closeness (i.e., being closer to the center of the networks) and the demographic similarity of diagnosis. The results of this study indicate that when given the opportunity, those with IDD provide social support to their peers. Additionally, shared life experiences, like diagnosis and sexuality are important in the feelings of belonging and appraisal; while, tangible support is most likely to come from outside the network and not from those in the program. Like the egocentric analysis chapter, the sociometric analysis eludes to differentiation between support structures and the types of roles that individuals play within the lives of those with IDD. Understanding network characteristics and the impact on mental health can assist in developing programs centered around relationships creation and retention.

## Implications for Future Research and Practice

The findings of this dissertation have important implications for public health research and practice. The aim for the dissertation was to explore the egocentric and sociometric networks of individuals with IDD, informed by gaps and findings in the literature. While literature suggests those with IDD have smaller networks, mainly comprised of family members and support staff (Cunningham et al., 2009; Forrester-Jones et al., 2006; Krauss et al., 1992), this study suggests when given the opportunity, individuals with IDD will provide support to each other, and there are differences in support provided when broken down into subcategories. In order for social support benefits to occur, any future program developers who work with those with disabilities need to provide the opportunity for people to come together and interact. This study provides evidence that the model in which the PATHS program utilizes effectively brings together people who experience IDD and creates an environment that allows relationships and support to flourish. Similar postsecondary education programs should mimic the PATHS model in order to create a healthy social setting. This dissertation supports the use of social network analysis in social support research and provides an example of multiple name generators (Marin & Hampton, 2007), which is a novel approach within egocentric network analysis. Social network analysis allows for the context of relationships and the attributes of the dyads (e.g., shared characteristics, specific support provided, value) to be the main focus of analysis instead of individual characteristics. While the field of social support is well-establish, this dissertation highlights the gaps in research using network-based methods to assess multiple types of social support for those with disabilities.

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## APPENDIX A

## EGOCENTRIC NETWORK SURVEY

1. What is your name?

____________________________________________________

2. What gender do you identify as?

○ Male

○ Female

○ Transgendered

○ Other ____________________________________________

3. What is your sexuality?

○ Straight

○ Gay/Lesbian

○ Bisexual

○ Pansexual

○ Other ____________________________________________

4. Over the last 2 weeks, how often have you been bothered by any of the following problems? (select the bubble that applies to the statement)

| | Not at all | Several days | More than half the days | Nearly every day |
|---|---|---|---|---|
| Little interest or pleasure in doing things | ○ | ○ | ○ | ○ |
| Feeling down, depressed, or hopeless | ○ | ○ | ○ | ○ |
| Trouble falling or staying asleep, or sleeping too much | ○ | ○ | ○ | ○ |
| Feeling tired or having little energy | ○ | ○ | ○ | ○ |
| Poor appetite or overeating | ○ | ○ | ○ | ○ |
| Feeling bad about yourself-- or that you are a failure or have let yourself or your family down | ○ | ○ | ○ | ○ |
| Trouble concentrating on things, such as reading the newspaper or watching tv | ○ | ○ | ○ | ○ |
| Moving or speaking more slowly that other people could have noticed. Or the opposite-- being so fidgety or restless that you have been moving around a lot more than usual | ○ | ○ | ○ | ○ |

5.  With these problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

- ○ Not difficult at all
- ○ Somewhat difficult
- ○ Very difficult
- ○ Extremely difficult

6. For each statement, provide one name of a person in your life.

a. If you were to go on a trip for the day, who would you invite to go with?

________________________________________________________

b. Who would you talk to if you needed to share private worries or fears?

________________________________________________________

c. If you were sick, who would help you with chores?

________________________________________________________

d. If you needed advice for handling a problem with your family, who would you talk to?

________________________________________________________

e. If you wanted to go to the movies, who would you invite?

________________________________________________________

f. If you needed some suggestions on a personal problem, who would you talk to?

________________________________________________________

g. If you wanted to go to lunch, who would you invite?

________________________________________________________

h. If you needed a ride somewhere, who would you ask?

________________________________________________________

i. If you needed $20, who would you ask for money?

____________________________________________________________

---

7. The following questions are going to be about the person from question a.

8. What is ${Q13/ChoiceTextEntryValue} gender?

○ Male

○ Female

○ Other ____________________________________________

9. How do you know ${Q13/ChoiceTextEntryValue}?

○ Parent

○ Sibling

○ Other family member

○ Caregiver/support staff

○ Friend

○ Doctor

○ Teacher

○ Other ____________________________________________

10 Do you trust ${Q13/ChoiceTextEntryValue}?

○ Definitely yes

○ A little

○ No

---

11. Did you meet ${Q13/ChoiceTextEntryValue} through the B2C/PATHS program?

○ Yes

○ No

12. The following questions are going to be about the person from question b.

13. What is ${Q14/ChoiceTextEntryValue} gender?

○ Male

○ Female

○ Other ________________________________________________

---

14. How do you know ${Q14/ChoiceTextEntryValue}?

○ Parent

○ Sibling

○ Other family member

○ Caregiver/support staff

○ Friend

○ Doctor

○ Teacher

○ Other ________________________________________________

15 Do you trust ${Q14/ChoiceTextEntryValue}?

○ Definitely yes

○ A little

○ No

16 Did you meet ${Q14/ChoiceTextEntryValue} through the B2C/PATHS program?

○ Yes

○ No

17 The following questions are going to be about the person from question c.

18 What is ${Q15/ChoiceTextEntryValue} gender?

○ Male

○ Female

○ Other ________________________________________________

19 How do you know ${Q15/ChoiceTextEntryValue}?

○ Parent

○ Sibling

○ Other family member

○ Caregiver/support staff

○ Friend

○ Doctor

○ Teacher

○ Other ________________________________________________

19 Do you trust ${Q15/ChoiceTextEntryValue}?

○ Definitely yes

○ A little

○ No

20 Did you meet ${Q15/ChoiceTextEntryValue} through the B2C/PATHS program?

○ Yes

○ No

21 The following questions are going to be the person from question d.

22 What is ${Q16/ChoiceTextEntryValue} gender?

○ Male

○ Female

○ Other ________________________________________________

23 How do you know ${Q16/ChoiceTextEntryValue}?

○ Parent

○ Sibling

○ Other family member

○ Caregiver/support staff

○ Friend

○ Doctor

○ Teacher

○ Other ________________________________________________

---

24 Do you trust ${Q16/ChoiceTextEntryValue}?

○ Definitely yes

○ A little

○ No

---

25 Did you meet ${Q16/ChoiceTextEntryValue} through the B2C/PATHS program?

○ Yes

○ No

26 The following questions are going to be about the person from question e.

27 What is ${Q17/ChoiceTextEntryValue} gender?

○ Male

○ Female

○ Other ________________________________________________

---

28 How do you know ${Q17/ChoiceTextEntryValue}?

○ Parent

○ Sibling

○ Other family member

○ Caregiver/support staff

○ Friend

○ Doctor

○ Teacher

○ Other ________________________________________________

---

29 Do you trust ${Q17/ChoiceTextEntryValue}?

○ Definitely yes

○ A little

○ No

30 Did you meet ${Q17/ChoiceTextEntryValue} through the B2C/PATHS program?

○ Yes

○ No

31 The following questions are going to be about the person from question f.

32 What is ${Q18/ChoiceTextEntryValue} gender?

○ Male

○ Female

○ Other ________________________________________________

33 How do you know ${Q18/ChoiceTextEntryValue}?

○ Parent

○ Sibling

○ Other family member

○ Caregiver/support staff

○ Friend

○ Doctor

○ Teacher

○ Other ________________________________________________

34 Do you trust ${Q18/ChoiceTextEntryValue}?

○ Definitely yes

○ A little

○ No

35 Did you meet ${Q18/ChoiceTextEntryValue} through the B2C/PATHS program?

○ Yes

○ No

36 The following questions are going to be about the person from question g.

37 What is ${Q19/ChoiceTextEntryValue} gender?

○ Male

○ Female

○ Other ________________________________________________

38 How do you know ${Q19/ChoiceTextEntryValue}?

○ Parent

○ Sibling

○ Other family member

○ Caregiver/support staff

○ Friend

○ Doctor

○ Teacher

○ Other ________________________________________________

39 Do you trust ${Q19/ChoiceTextEntryValue}?

○ Definitely yes

○ A little

○ No

40 Did you meet ${Q19/ChoiceTextEntryValue} through the B2C/PATHS program?

○ Yes

○ No

41 The following questions are going to be about the person from question h.

42 What is ${Q20/ChoiceTextEntryValue} gender?

○ Male

○ Female

○ Other ________________________________________________

43 How do you know ${Q20/ChoiceTextEntryValue}?

○ Parent

○ Sibling

○ Other family member

○ Caregiver/support staff

○ Friend

○ Doctor

○ Teacher

○ Other ________________________________________________

---

44 Do you trust ${Q20/ChoiceTextEntryValue}?

○ Definitely yes

○ A little

○ No

---

45 Did you meet ${Q20/ChoiceTextEntryValue} through the B2C/PATHS program?

○ Yes

○ No

46 The following questions are going to be about the person from question i.

47 What is ${Q21/ChoiceTextEntryValue} gender?

○ Male

○ Female

○ Other ________________________________________________

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

48 How do you know ${Q21/ChoiceTextEntryValue}?

○ Parent

○ Sibling

○ Other family member

○ Caregiver/support staff

○ Friend

○ Doctor

○ Teacher

○ Other ________________________________________________

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

49 Do you trust ${Q21/ChoiceTextEntryValue}?

○ Definitely yes

○ A little

○ No

50 Did you meet ${Q21/ChoiceTextEntryValue} through the B2C/PATHS program?

○ Yes

○ No

## APPENDIX B

### SOCIOCENTRIC NETWORK SURVEY

1. If you needed to talk to someone about issues in your life (e.g., family, friends, work), who in the PATHS program would you go to? (select all names)

☐ Name 1

☐ Name 2

☐ Name 3

2. If you wanted to do a fun activity (e.g., go to the movies, shop, watch a sport), who in the PATHS program would you do the activity with? (select all names)

☐ Name 1

☐ Name 2

☐ Name 3

3. If you needed money or a place to live, who in the PATHS program would you ask? (select all names)

☐ Name 1

☐ Name 2

☐ Name 3

- - -

4. Who in the PATHS program do you trust and care for? (select all names)

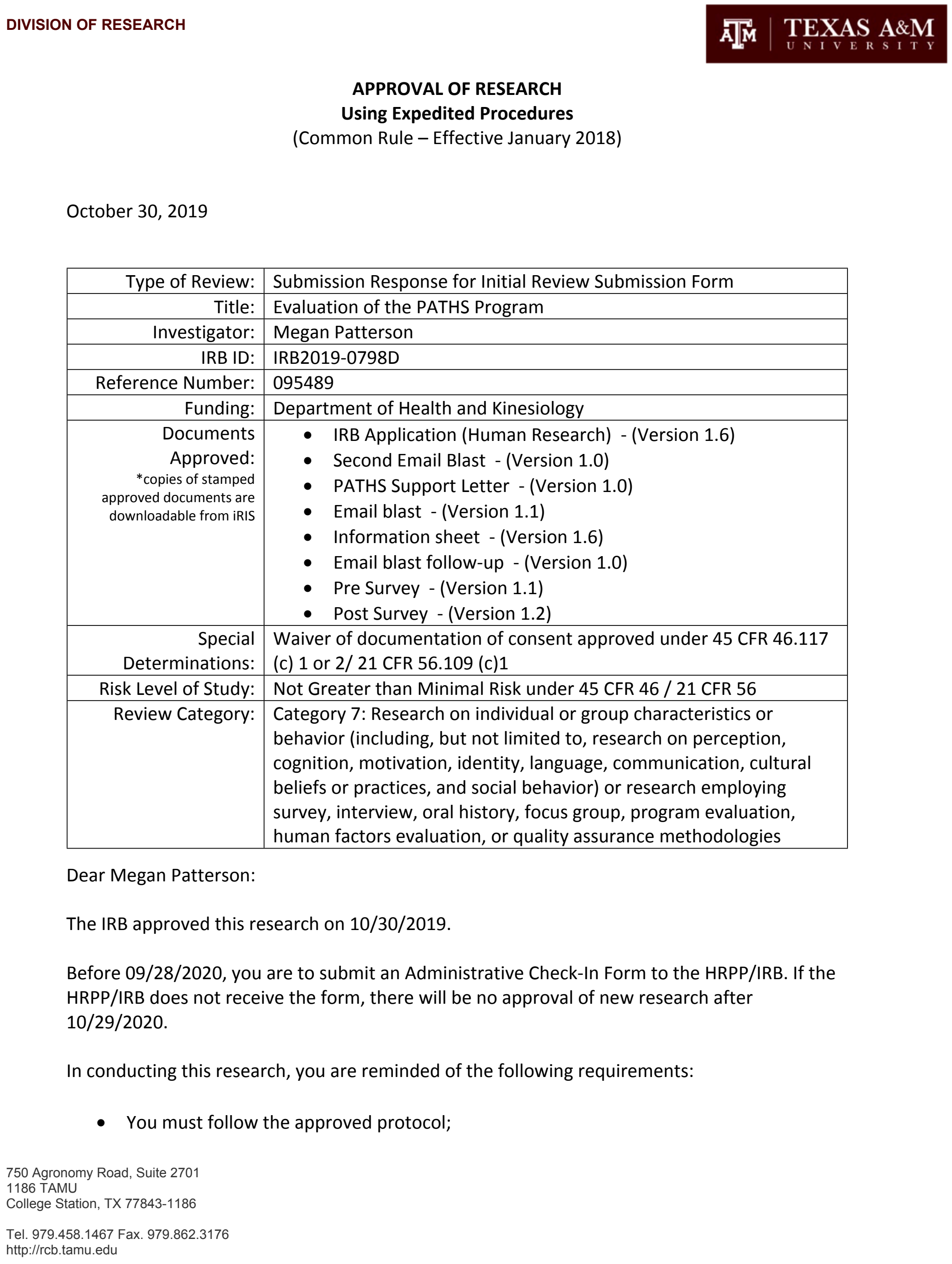
☐ Name 1

☐ Name 2

☐ Name 3

# APPENDIX C

## IRB APPROVAL



DIVISION OF RESEARCH

TEXAS A&M UNIVERSITY

**APPROVAL OF RESEARCH**
**Using Expedited Procedures**
(Common Rule – Effective January 2018)

October 30, 2019

| | |
|---|---|
| Type of Review: | Submission Response for Initial Review Submission Form |
| Title: | Evaluation of the PATHS Program |
| Investigator: | Megan Patterson |
| IRB ID: | IRB2019-0798D |
| Reference Number: | 095489 |
| Funding: | Department of Health and Kinesiology |
| Documents Approved:<br>*copies of stamped approved documents are downloadable from iRIS | • IRB Application (Human Research) - (Version 1.6)<br>• Second Email Blast - (Version 1.0)<br>• PATHS Support Letter - (Version 1.0)<br>• Email blast - (Version 1.1)<br>• Information sheet - (Version 1.6)<br>• Email blast follow-up - (Version 1.0)<br>• Pre Survey - (Version 1.1)<br>• Post Survey - (Version 1.2) |
| Special Determinations: | Waiver of documentation of consent approved under 45 CFR 46.117 (c) 1 or 2/ 21 CFR 56.109 (c)1 |
| Risk Level of Study: | Not Greater than Minimal Risk under 45 CFR 46 / 21 CFR 56 |
| Review Category: | Category 7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies |

Dear Megan Patterson:

The IRB approved this research on 10/30/2019.

Before 09/28/2020, you are to submit an Administrative Check-In Form to the HRPP/IRB. If the HRPP/IRB does not receive the form, there will be no approval of new research after 10/29/2020.

In conducting this research, you are reminded of the following requirements:

- You must follow the approved protocol;

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