EXAMINING THE LINK BETWEEN SUPPORTS AND OUTCOMES: THE MEDIATING ROLE OF SELF-DETERMINATION FOR ADULTS RECEIVING LONG TERM SERVICES AND SUPPORTS

By

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Abstract: The current study used a Causal Agency (Shogren et al., 2015; Shogren, 2016) lens to examine the relations between the caregiver relationship type, self-determination, and social determination of individuals with intellectual and developmental disabilities (IDD) in order to gain a better understanding of the predictive relation of caregiver relationship on social determination and the mediating effect of self-determination. Using a sample of 193 caregivers and 193 individuals with IDD, three research questions were examined: How are self-determination and social determination related? How does the caregiver relationship predict social-determination? Does self-determination mediate the relationship between caregiver relationship and social determination? Findings show that self-determination and social determination are not significantly related. These results do not corroborate with previous research and suggest a need for an examination of the social determination construct. Additional findings suggest that caregiver relationship and self-determination are significant predictive factors regarding an individual's dating choices. Further findings show that self-determination does not mediate the relationship between caregiver relationship and social-determination. These results indicate that self-determination does not explain the link between caregiver relationship and social-determination. Implications of this study are important for policy-makers, practitioners, and caregivers who can help foster self-determination in order to help individuals achieve a higher quality of life.

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CHAPTER I

INTRODUCTION

Historically, individuals with intellectual and developmental disabilities (IDD) have not had the opportunity to make choices pertaining to their lives (Hewitt, Agosta, Heller, Williams, & Reinke, 2013). This has contributed to their lack of control in the decision making process; therefore, hindering their self-determination (Shogren, 2016). For individuals with IDD, supporting and promoting self-determination is considered best practice (Shogren, 2016). Research into self-determination, specifically how to increase self-determination, is on the rise and one of the most prominent areas of interest within the IDD population (Shogren, 2016). The environment an individual interacts with mediates an individual's self-determination (Shogren, 2013); therefore, examining the influence of caregiver type is important in understanding predictors of self-determination. Shogren (2013) presents theoretical support of environmental influencers for analyzing the impact of caregiver type on self-determination.

Most individuals with IDD rely on daily support from a caregiver. A caregiver is someone who provides care for another individual (Greene, Aranda, Tieman, Fazekas, & Currow, 2012), such as transportation and assisting in daily activities. Caregivers are often an unpaid parent, sibling, or other family member as well as a Direct Support Professionals (DSPs) (Hewitt et al., 2013). Although the majority of individuals with IDD live in the family home (Hewitt et al., 2013), a smaller portion, approximately 8 percent live outside the family home in the community and are receiving long-term support and services (LTSS) through a Medicaid Home and Community Based Services (HCBS) waiver (Braddock et al., 2015; Larson et al., 2015).

Individuals living in the family home may also receive LTSS, but are not receiving residential supports. Individuals who are receiving HCBS typically live in community-based residential settings such as family homes, group homes, and homes receiving daily living supports (DLS). Services an individual receives are aids an individual receives to function in his/her daily life (e.g., transportation, residential, etc.). Understanding an individual's satisfaction with his/her services is crucial in understanding the impact of receiving LTSS.

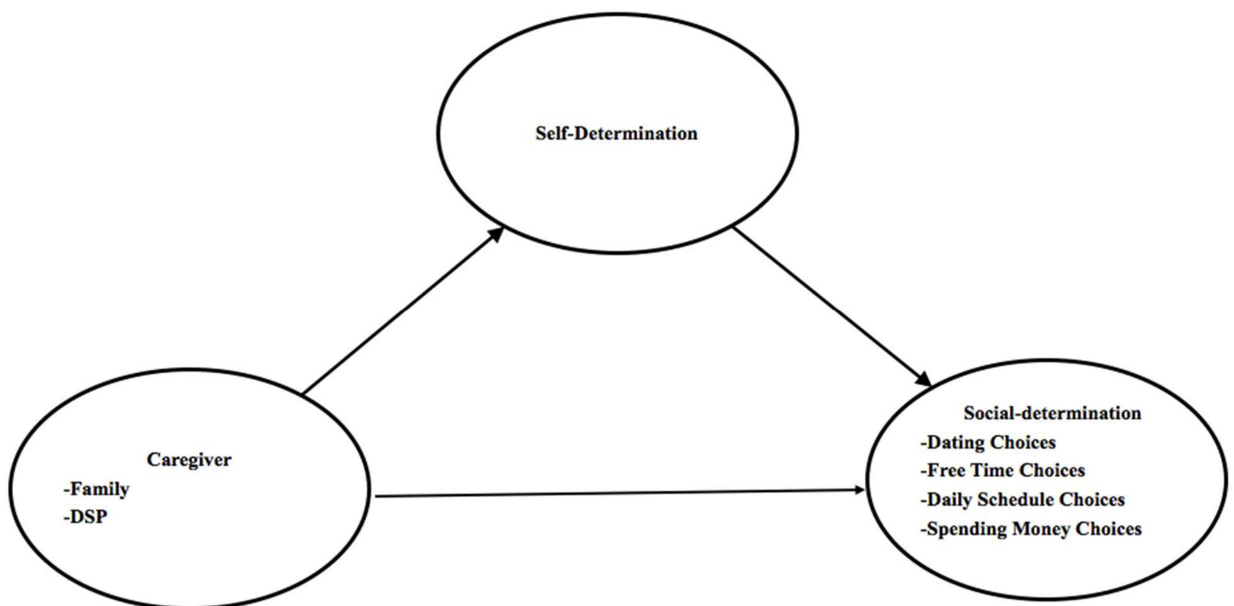
Self-determination is the individual acting as the causal agent in his/her life choices (Shogren et al., 2015; Shogren 2016); whereas, social determination is the individual participating in the decision-making process with supports (Mehling & Tassé, 2014; Mehling & Tassé, 2015). Social determination is an emerging latent variable measuring outcomes (Mehling & Tassé, 2014; Mehling & Tassé, 2015). Thus, it is important to examine the unique relation caregiver type (family or DSP) and residential setting has with social determination. Individuals that participate in the daily decision-making process are more likely to be self-determined (Shogren, 2016) as well as more satisfied with the choices (Duvdevany, Ben-Zur, & Ambar, 2002; Morningstar et al., 2010). Yet, research surrounding self-determination's mediating effect on the link between an individual's caregiver and his/her social determination is limited. To address these gaps in the literature, the current study has three research goals:

1. The first goal is to examine the potential link between the caregiver relationship (Family or DSP) and social determination (Individual items: Can you go on a date if you want to? Who decides what you do in your free time? Who decides your daily schedule? Do you choose what you buy with your spending money?)
2. The second goal is to examine the potential link between self-determination and social-determination.

3. The third goal is to examine the potential mediating effect of self-determination on the relationship between caregiver relationship (Family or DSP) and social determination (Individual items: Can you go on a date if you want to? Who decides what you do in your free time? Who decides your daily schedule? Do you choose what you buy with your spending money?)

Figure 1

Hypothesized mediating effect of self-determination



CHAPTER II

LITERATURE REVIEW

The following review of literature will consist of seven sections. First, a brief overview of theories pertaining to self-determination. Next, there is an evaluation of home and community based services in the Oklahoma. The following section is a synopsis of the residential settings in which individuals with intellectual and developmental disabilities (IDD) typically live. Then, a summary of caregivers in the IDD field is provided. The fifth section explains the operationalization of self-determination in previous research studies. The following section provides the operationalization of social determination in previous literature. The final section of the literature review provides a brief summary of the literature review, research questions, and hypotheses.

Self-determination theories

In order to examine self-determination in theories, a clear definition of self-determination must be established**.** Self-determination has been defined in a variety of ways, yet the theme remains the same. The main theme of self-determination is having control over one's own life choices and making decisions without influence. According to leaders in the field of IDD, self-determination is the behavior of an individual who controls his or her life choices without

interference from or effect of unwarranted exterior forces, pertaining to an individual's quality of life (Howard & Howard, 2000; Jenkins, 1996; Wehmeyer & Schwartz, 1998; Wehmeyer, 1999; Wehmeyer, 2005). An individual who has opportunity and exercises control over his or her life choices is someone who is self-determined. An individual's self-determination is commonly measured by looking at four different internal factors: autonomy, self-regulation, psychological empowerment, and self-realization. An individual who is self-determined is able to regulate his/her behavior: act more independently, is psychologically empowered, and is self-realizing (Wehmeyer, 1999). Self-regulation of behavior is the ability to progress from a dependent state into a more independent state pertaining to care from others (Wehmeyer & Kelchner, 1995a; Wehmeyer, 1999). Autonomy is the ability to act more independently in daily tasks (Wehmeyer, 1999). Psychological empowerment refers to an individual's perceived control of multiple dimensions including cognition, personality, and motivational domains (Zimmerman, 1990). Self-realization is an individual's ability to be self-aware and understand the capacity of his/her knowledge (Wehmeyer, 1999). Each of these dimensions factor into an individual's overall self-determination.

Wehmeyer (2005) conducted a synthesis on the definitions of self-determination. Wehmeyer found the following themes as misinterpretations in his definition analysis of self-determination: it is a process or outcome, a set of skills, independent performance of behaviors, self-reliance, or self-sufficiency; self-determined behavior is always successful, something you do, and a just choice (Wehmeyer, 2005). Therefore, these definitions should be avoided when defining self-determination as a whole. Within his review, he found that it is important to avoid using the word control synonymously with self-determination. Individuals with self-determination do not have control over their lives, yet they have control over the decisions they make regarding their lives (Wehmeyer, 2005). This is important to note because individuals are determined if they are the determining factor in choices and opportunities. An acceptable

definition of self-determination is the action of determining choices, actions, goals, and solutions (Wehmeyer, 2005). Thus, the individual is the decision maker in his or her life. Wehmeyer has also framed self-determination within A Functional Model of Self-Determination (1999). This model shows the influence an individual's capacity, supports, and opportunity has on his or her self-determination. This model has been used to examine self-determination in the lives of individuals with IDD, and has been used as a stepping-stone for other frameworks and definitions. The Functional Model of Self-Determination has aided in taking the focus off the individual and onto to the relationship the individual has with contextual factors surrounding the individual.

Another definitional framework within the self-determination literature is the Causal Agency Theory, which is an extension of Wehmeyer's Functional Model of Self-determination (Shogren et al., 2015; Shogren, 2016). This theory explains how individuals become self-determined as well as what environmental factors influence an individual's level of self-determination (Shogren et al., 2015; Shogren, 2016). Within this theory, self-determination is defined as:

> A dispositional characteristic manifested as acting as the causal agent in one's life. Self-determined people (i.e., casual agents) act in service to freely chosen goals. Self-determined actions functions to enable a person to be the causal agent in his or her life (Shogren et al., in press).

This definition of self-determination focuses on the interaction between the individual and the contextual factors surrounding the individual (Shogren et al., 2015; Shogren, 2016). The interaction between the environment and person is not the only way to understand or define self-determination. By examining self-determination in the Quality of Life paradigm, we can gain a broader understanding of self-determination.

Individuals that have high levels of self-determination also report having a high level of quality of life (Lachapelle et al., 2005). Self-determination is one of eight key elements of an individual's quality of life (Felce & Perry, 1995; Schalock, 1997; Wehmeyer & Schwartz, 1998). This is important to note due to the amount of research surrounding quality of life and self-determination. By understanding what self-determination is related to, readers can better understand the concept. Thus, reviewing outcomes associated with self-determination is an important step in comprehending how direct service providers and family caregivers can influence self-determination.

Fostering Self-Determination. Self-determination can increase and decrease throughout an individual's lifetime (Jenkins, 1996). Self-determination can be fostered in early childhood by informal supports such as family members or special education teachers (Shogren, Plotner, Palmer, Wehmeyer, & Paek, 2014; Turnbull & Turnbull, 2001; Wehmeyer, 2014; Windley & Chapman, 2010), and continues to be influenced into adulthood (Wehmeyer & Shogren, 2016). Shogren (2016) states that individuals provided with instruction, opportunity, and support become more self-determined. This is important to note because it shows that there are external factors that affect the variation of an individual's self-determination. Involving individuals in planning processes increases the satisfaction of transitions as well as their self-determination (Morningstar et al., 2010). By simply encouraging decision-making and involving individuals in the process of making decisions, caregivers can help promote self-determination.

Individuals who do not have a disability are typically more self-determined than their peers with disabilities (Shogren, Kennedy, Dowsett, & Little, 2013). This is not due to cognition, but to the lack of opportunities for individuals to make decisions in their lives (Wehmeyer & Bolding, 1999; Wehmeyer & Bolding, 2001). An individual's social skills are also predictors of self-determination, thus encouraging social skills is an indirect way to support self-determination (Pierson, Carter, Lane, & Glaeser, 2008). According to Shogren (2013), "Environmental

opportunities mediate the relationship between intelligence and self-determination" (p. 496). Examining the environment in which the individual lives is important in understanding what opportunities are available and who (e.g., family or DSP) supports the individual in decision-making. In order to foster self-determination, families need to encourage decision-making and let their family members engage in different opportunities, such as acting independently in daily activities (Turnbull & Turnbull, 2001; Wehmeyer, 2014). Encouraging individuals to make decisions is a prominent way to foster self-determination. It is clear that supports influence an individual's level of self-determination, thus a better understanding of how different supports and services influence adults with IDD is an important area of research to continue to explore.

Home and Community Based Services

In the early 1980s, Medicaid introduced Home and Community-Based Services (HCBS) for individuals with developmental disabilities (Hewitt, Nord, Bogenschutz, & Reinke, 2013). The introduction of these services helped individuals move from institutional residential settings into community residential settings (Hewitt et al., 2013). Oklahoma Department of Human Services Developmental Disabilities Services (OKDHS-DDS) administers three HCBS waivers for adults: Community Waiver, In-Home Supports Waiver, and the Homeward Bound Waiver. Waiver recipients must have a primary diagnosis of intellectual disability (Oklahoma Medicaid Agency, 2011). Understanding the different waiver types will give insight to the different levels of supports and services available to individuals.

The Community waiver gives individuals access to on average $75,000 in supports and services (K. Ryal, Personal Communication, 2017). This waiver has no cap on the amount of financial support an individual can receive. Within Oklahoma, residential supports can vary on the type of residential setting and the amount staff support an individual receives.

In Oklahoma, individuals who request services must wait an average of ten years before services become available, yet the list continues to grow each year (OKDHS-DDS, 2107). Once individuals are off the waiting list and eligible for services, they are only administered the In-Home Supports Waiver (J. Jones, Personal Communication, 2016). The In-Home Supports waiver gives individuals with ID access to a capped $21,600 in supports and services (OKDHS-DDS, 2007). Since the waiver is capped at a small amount of funds, the supports and services are minimal compared to other waivers in Oklahoma. The In-Home Supports waiver is common with individuals who live in the family home (NCI, 2016). Since individuals receiving the IHSW receive less support from the state, they depend on more support from their family. Another waiver that is unique to Oklahoma and important to review is the Homeward Bound Waiver.

The Homeward Bound waiver is for individuals 18 years or older who were members of the plaintiff class in the *Homeward Bound v. The Hissom Memorial Center* case. Individuals who receive the Homeward Bound waiver gain access to a considerably higher amount of financial support due to the settlement. Recipients of the Homeward Bound waiver receive on average $200,000 in supports and services, (K. Ryal, Personal Communication, 2017). A common setting for these individuals is a DLS where they live either alone or with one or two housemates. They are able to live alone due to the amount of funding administered through their waiver type. This large amount of funding also gives them access to more one on one staffing compared to other waiver types.

Understanding the different waiver types helps establish a base of understanding in how supports and services vary. Waiver types vary on the amount and type of support an individual receives. For instance, an individual on the Homeward Bound Waiver will receive more residential support compared to an individual on the Community Waiver. Some individuals choose to opt out of receiving residential support; however, they still receive support outside of

the home. Cases like these are classified as Community Waiver Non-residential or the In-Home Supports Waiver. Examples of non-residential support are transportation and vocation.

Residential Settings

Individuals with IDD typically live in the family home, institutional facilities, nursing homes, intermediate-care facilities, or in their own house (Hewitt et al., 2013). However, there has been a recent shift from institutional settings into more integrated community based residential settings (Hewitt et al., 2013). The amount of individuals living in larger residential settings such as institutions and nursing homes has been trending downwards since the deinstitutionalization movement of the 1970s (Hewitt et al., 2013; Larson et al., 2014). Thus, the individuals who left these larger congregate settings moved into smaller community based settings (Hewitt et al., 2013), resulting in higher life satisfaction (Duvdevany, Ben-Zur, & Ambar, 2002). There are multiple models of community-based residential settings in which individuals reside.

Typical models of group-residential settings in Oklahoma include Daily Living Supports (DLS), Group Home Large (GHL), Group Home Small (GHS), and Alternative Group Home (AGH). Smaller models of residential settings in Oklahoma that typically house one or two individuals include Agency Companion (AC) and Specialized Foster Care (SFC) (OKDHS-DDS, 2010). A DLS residential setting is a typical house within the community that houses 1-3 residents with ID. DLS homes receive an average 24 hours of staffing (OKDHS-DDS, 2010). This level of staffing is achieved by the residents pooling together their units of staffing in order achieve 24-hour staffing (OKDHS-DDS, 2007). Group homes operate with either 4-6 residents (GHS) or 7-15 residents (GHL). Group homes are houses typically designed to facilitate the patient-caregiver relationship. These purpose-built homes are designed to support the residents in their daily lives (i.e., wheel chair ramps, hand rails, lifts, etc.). Alternative Group Homes are

similar to GHS and GHL, yet they typically house residents with a history of behavior problems and criminal records. AC and SFC are similar in that the individual lives in a home with a family who provides care for them. These settings typically house one resident, although there are circumstances where two residents live in the same placement (OKDHS-DDS, 2010). Residential settings are important to note because much like the entire nation, Oklahoma is shifting away from state and agency operated supports and services towards a more family centric/dependent plan of supports and services (Heller, Gibbons, & Fisher, 2016).

Since the deinstitutionalization movement, individuals with IDD continue to shift away from larger residential settings to smaller more integrated living situations (Hewitt et al., 2013; Larson et al., 2014). This shift is not only effecting where the individual lives, but also the responsibilities of the caregiver who is providing daily care for the individual. The residential setting in which an individual lives has an impact on the type of caregiver he or she will be receiving support from. For instance, individuals living in group homes or houses with daily living supports are more likely to be receiving care from a DSP, rather than a familial caregiver. Likewise, an individual that lives in the family home will typically receive the majority of their daily support from a familial caregiver (Owen et al., 2016).

Caregivers

There are approximately 641,000 individuals with IDD that rely on daily support from caregivers (Heller, Gibbons, & Fisher, 2015). A caregiver is an individual that offers care for another individual (Greene et al., 2012). Often times, this role is a parent, sibling, or other family member as most caregivers are unpaid family members (Hewitt et al, 2013). Individuals who live in the family home primarily receive their care from family members; however, many individuals on a waiver receive limited in-home support from a paid caregiver or a DSP (Heller et al., 2015; Hewitt et al., 2013). As the population of individuals with IDD rises, so does the demand for

caregivers. There are multiple types of caregivers in the IDD community, yet for this review caregivers have been categorized as either a caregiver who is DSP or a caregiver who is family. It is estimated that 71percent of individuals with IDD receive daily support from a family member (Heller et al., 2015). Typically, the mother is the primary caregiver, yet the family unit as a whole act as a support system for the individual across his/her lifespan (Heller, Hsieh, & Rowitz, 2000). As the primary caregiver ages, siblings often take on the primary caregiving role (Heller & Kramer, 2009). Family caregiving is the primary source of support for the IDD population, yet the demand for DSPs is rising (Heller et al., 2015). The demand for non-familial supports for the individual reflect the burden that is lifelong caregiving (Hewitt, Agosta, Heller, Williams, & Reinke, 2013). Thus, examining the unique influence caregivers have on an individual's self-determination is crucial in providing better supports and services for individuals with IDD.

Operationalization of self-determination.

Individuals who report having a higher level of self-determination are likely to report having a higher level of quality of life and life satisfaction (Lachapelle et al., 2005; McDougall, Evans, & Baldwin, 2010; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Wehmeyer & Schalock, 2001; Williams et al., 2009). The association between self-determination and quality of life shows the importance of individuals having control over the decision-making process in their own lives and the effect it has on their quality of life and life satisfaction. Studies show employment satisfaction and community inclusion are outcomes associated with individuals who are highly self-determined (Wehmeyer & Schwartz, 1997; Wehmeyer & Bolding, 2001; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2013). The association between self-determination and employment supports the notion that individuals who determine where they work are more likely to be satisfied with their employment. Another result from the study shows support for individuals who get to determine where they are involved in the community are more likely to get involved and return (Shogren et al., 2013). Individuals who are self-determined are more likely to

actively participate in their community (Shogren et al., 2013). Individuals who are self-determined are also more likely to have a job out in the community rather than work at a sheltered workshop (Shogren et al., 2013). According to Wehmeyer et al. (2011), self-determination is not solely dependent on the individual's skills, knowledge, or beliefs, but the interaction between the environment and the individual (Wehmeyer, Kelchner, & Richards, 1995). Once again, this takes the focus off the individual and places it back on the interaction between the individual and his/her environment. Thus, outcomes related to self-determination may be moderated by contextual factors such as supports and services. According to Shogren (2013), "Environmental opportunities mediate the relationship between intelligence and self-determination" (p. 496). This shows that the self-determination is not dependent on individual characteristics but on the environment the individual interacts with. If the environment is supportive of decision making and encourages the individual to be a causal agent, then the individual should become more self-determined. According to Shogren (2016), individuals with IDD are able to achieve higher levels of self-determination if the proper instruction, opportunities, and supports are provided. The individual must also be goal orientated and have outcomes he or she desires to obtain (Wehmeyer et al., 2011). Although the field has shifted from focusing solely on the individual, it is still important to take into consideration the effects of personal characteristics on an individual's level of self-determination (Wehmeyer & Garner, 2003). Thus, while examining self-determination, researchers need to focus on how the individual interacts with his or her environment, as well as how the individual is influenced by his or her environment. The next section of the review will briefly examine how self-determination is currently being fostered in the IDD population today.

Social-determination.

Social determination within the IDD field is a relatively new concept. This is an emerging concept used to measure outcomes related to an individual's participation in the decision-making process. Recent studies have conceptualized social determination as an

individual's participation in the decision-making process (Mehling & Tassé, 2014; Mehling & Tassé, 2015).

Mehling and Tassé (2014) sought to derive a model for social outcomes and associated constructs for individuals with Autism Spectrum Disorder (ASD) and other disabilities. This study included 1,772 participants pulled from two larger National Core Indicators (NCI) studies with 20,395 participants from the years 2009-2011. In order to be included in the study, the individual must have a diagnosis of ASD (Mehling & Tassé, 2014). The sample was divided into two groups with one group being diagnosed with ASD (*n* = 886, 85.6% with ID) and the second group with a developmental disability other than ASD (*n* = 886, 94.4% with ID). This study examined items from the Social Relationships, Community Inclusion, and Opportunity of Choice indicators previously constructed by NCI. Personal Control, Social Determination, and Social Participation and Relationships all emerged as factors from the analysis. These factors emerged through the use of exploratory factor analyses (EFA) and then confirmed using a confirmatory factor analysis (CFA) (Mehling & Tassé, 2014). Overall, this study found that the Personal Control, Social Determination, and Social Participation and Relationships constructs had a superior fit compared to the NCI measurement model (Mehling & Tassé, 2014).

Mehling and Tassé (2015) continued their research on the Personal Control, Social Determination, and Social Participation and Relationships constructs by examining the relationships between the constructs. Using structural equation modeling (SEM) researchers compared group differences between individuals with ASD (*n* = 886) and individuals with other developmental disabilities (*n* = 886) (Mehling & Tassé, 2015). The SEM analysis showed support for significant relationships between the personal control, social-determination, and social participation and relationships constructs. More specifically, results show support for a positive and significant relationship between control and social determination (Mehling & Tassé, 2015).

Drs. Mehling & Tassé (2015) have conceptualized social determination as participating in the decision making process; however, further research into the concept needs to be conducted.

Individuals that participate in the decision-making process are more likely to be satisfied with the choices being made (Duvdevany, Ben-Zur, & Ambar, 2002; Morningstar et. al., 2010). Decision-making is related with social outcomes, interpersonal relationships, and community integration (Mehling & Tassé, 2015). Individuals with IDD that make more of their own choices are more likely to spend time interacting with friends and integrating into the community (Heller, Miller, Hsieh, & Sterns, 2000; Mehling & Tassé, 2015). Making decisions regarding one's own life is associated with life satisfaction (Heller et al., 2000).

Summary

In summary, self-determination is associated with positive outcomes including decision-making (social-determination), quality of life (Heller et al., 2000; Lachapelle et al., 2005; McDougall, Evans, & Baldwin, 2010; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Wehmeyer & Schalock, 2001; Williams et al., 2009), and community inclusion (Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2013; Wehmeyer & Schwartz, 1997; Wehmeyer & Bolding, 2001). This literature review has provided a knowledge base surrounding the importance of self-determination and the many positive social outcomes related to it. Self-determination is the individual acting as the causal agent in his/her life choices (Shogren et al., 2015; Shogren 2016); whereas, social determination is the individual participating in the decision-making process with supports (Mehling & Tassé, 2014; Mehling & Tassé, 2015). Yet, there seems to be a lack of literature focusing on what influences self-determination, and how self-determination mediates the link between supports and social-determination.

Research Question 1. How are self-determination and social determination related?

Hypothesis 1: Self-determination and social determination will be positively and significantly related.

Research Question 2. How does the caregiver relationship (Family or DSP) predict social determination (Individual items: Can you go on a date if you want to? Who decides what you do in your free time? Who decides your daily schedule? Do you choose what you buy with your spending money?)

Hypothesis 2: Individuals whose primary caregivers are DSPs will be more likely to have the opportunity to make choices regarding dating and will be more likely to decide what they purchase with spending money.

Hypothesis 3: Individuals whose primary caregivers are family members will be more likely to choose what they do in free time and during their daily schedule.

Research Question 3. Does self-determination mediate the relationship between caregiver relationship (Family or DSP) and social determination (Individual items: Can you go on a date if you want to? Who decides what you do in your free time? Who decides your daily schedule? Do you choose what you buy with your spending money?)

Hypothesis 4: Self-determination will account for the relation between caregiver relationship and social-determination. The indirect effect will be greater than the direct effect.

CHAPTER III

METHOD

The current study is part of a larger research study, Oklahoma National Core Indicators (OK-NCI), conducted by Drs. Jennifer Jones and Kami Gallus. Drs. Jones and Gallus contract with the Oklahoma Department of Human Services –Developmental Disabilities Services (OKDHS-DDS) to collect the National Core Indicators Adult Consumer Survey with adults receiving Home and Community Based Services (HCBS) in Oklahoma. The OK-NCI project's purpose is to assess the outcomes of services provided to individuals with IDD and their families. The purpose of the current study is to examine the link between the caregiver relationship and social-determination, to examine the link between self-determination and social-determination, and to examine the mediating effect of self-determination on the relationship between caregiver relationship and social determination.

Procedures

Approval for the Oklahoma National Core Indicators research study, led by Drs. Jennifer Jones and Kami Gallus, and secondary data analysis for the current study was gained from Oklahoma State University's institutional review board. Participants for this study were part of a representative random sample, of adults in Oklahoma receiving Medicaid Home and Community Based Services (HCBS) across three waivers: Homeward Bound Waiver, Community Waiver, In-Home Supports Waiver. Recruitment was facilitated by trained undergraduate and graduate

student assistants on the Oklahoma NCI research team. Research team members called and scheduled in-home visits with the individual, the individual's staff, or family caregiver. During the in-home visit, a research team member would read a script explaining the survey and its intent (See Appendix A), and then ask the individual if he/ she was willing to participate. If the individuals were unwilling or unable to complete the Adult Consumer Survey, research team members secured their consent before gathering information from their caregivers. The Adult Consumer Survey and Arc's Self-Determination Scale: Short Form Adult Version were conducted with a research team member during the in-home visit. A research team member would invite the caregiver to complete the Caregiver Surveys while the team member administered the ACS and SDS-SFA to the individual with ID. Administration of the surveys took approximately 45 minutes.

Participants

The sample in this study was taken from a larger sample collected through the 2014-2105 OK-NCI project (N = 1053). The inclusion criteria for this research study is completion of the Self-Determination Scale and Adult Consumer Survey by the individual and completion of the caregiver surveys by the caregiver. The total participants in the current study include 193 individuals (n = 108 male, n = 85 female) with intellectual disability (n = 139 mild, n = 42 moderate, n = 9 severe, n = 2 profound, n = 1 unspecified) and their caregivers (n = 42 males, n = 151 female). Individuals ranged in age from 18 to 74 years (M = 47.6, SD = 14.4) and caregivers ranged in age from 19 to 74 years (M = 45.6, SD = 14.5). Caregiver relationships include family (e.g. parent, sibling, grandparent, foster-parent/ agency-companion) and direct service provider (DSP). It is possible for a caregiver to be a family member as well as a DSP or agency

companion. If the caregiver is both a family member and DSP, he/she is considered a familial caregiver. Agency companions and foster-parents were considered familial caregivers due to the longevity of the relationships ranging from 6 years to 30 years. Table 1 provides a summary of the individual's characteristics and Table 2 provides a summary of caregiver characteristics.

Table 1

Descriptive Statistics for Individuals (N = 193)

	Mean	SD	Range
Age	47.6	14.4	18-74
		n	%
Gender			
Female		85	44.0
Male		108	56.0
Race			
American Indian or Alaska Native		16	8.3
African American		18	9.3
White		152	78.8
Hispanic/Latino		3	1.6
Two or more races		4	2.1
Level of ID			
Mild		139	72.0
Moderate		42	21.8
Severe		9	4.7
Profound		2	1.0
Unspecified		1	0.5
Residential Settings			
Daily Living Supports*		151	78.2
Group Home**		11	5.7
Family Home		31	16.1

*Daily Living Supports include individuals that live in their own home or with 2-3 persons with IDD also receiving residential supports

**Group Home includes small group homes (4-6) and large group homes (7-15)

Table 2

Descriptive Statistics for Caregivers (N = 193)

	Mean	SD	Range
Age	45.6	14.5	19-74
		n	%
Gender			
Female		151	78.2
Male		42	21.8
Race/ Ethnicity			
American Indian or Alaska Native		16	8.3
African American		39	20.2
Caucasian		120	62.2
Hispanic/Latino		4	2.1
Other races not listed		1	0.5
Two or more races		12	5.1
Relationship Type			
Familial		31	16.1
Parent		22	
Sibling		3	
Grandparent		2	
Foster Parent/ AC		4	
Direct Support Professional		162	83.9

Measures

National Core Indicators Adult Consumer Survey. The National Core Indicators (NCI) Adult Consumer Survey (ACS) was first developed and piloted in 1997 by seven states participating in in the National Association of State Directors of Developmental Disability Services and the Human Services Research Institute (National Core Indicators, 2015). The ACS evaluates service outcomes for individuals who have developmental disabilities and receive

services funded by the state. The ACS examines the individual's outcomes through 130 items by addressing the following domains and subdomains: Individual Outcomes (Work, Community Inclusion, Choice and Decision-Making, Self-Determination, Relationships, Satisfaction), Health, Welfare, and Rights (Safety, Health, Medications, Wellness, Respect/ Rights), and System Performance (Service Coordination, Access) (National Core Indicators, 2015). The ACS consists of three sections: Background Information, Section One, and Section Two. This instrument has adequate reliability with inter-rater agreement of 93% and a kappa score of 0.794 (National Core Indicators, 2012). Background Information contains 58 items pertaining to basic demographic data and factual information concerning the individual's personal characteristics, health history, employment, residence, and levels of supports and services. Background information is collected through mining the individual's OKDHS-DDS records and information provided by the individual's caregiver via phone calls or during the face-to-face visit. Section One contains 42 items regarding the individual's home, employment and other daily activities, safety, friends & family, community participation, rights & privacy, and satisfaction with supports and services. Items in Section One can only be answered by the individual during the face-to-face visit because these items are subjective and represent the individual's opinion (e.g., *Do you like your home?*). Section Two contains 30 items regarding the individual's community inclusion, choices, rights, access to services, and health and wellness. These items can be answered by the individual or by a proxy respondent who is familiar with the individual's daily routine and represent more factual information (e.g., *How many times did you go shopping in the last month?*).

Social-determination. For the purpose of the current study, four items from Section One and Section Two of the ACS were used as social determination variables: Section One: *can you*

go on a date if you want to? Section Two: *Who decides your daily schedule? Who decides what you do in your free time? Do you decide what you buy with your spending money?* Table 3 includes response codes, with higher scores indicating higher levels of social-determination. Responses that were recorded as "don't know" or "Not Applicable" were not included in the analysis. Responses were recoded using the same coding system as Mehling and Tassé (2014). In this study Cronbach's Alpha was used as an indicator of reliability of the social determination sub-scale (α= .389). Due to the low reliability of the social determination subscale, responses from individual items will be analyzed as the outcome variables.

Table 3

Response Codes for Social Determination Questions

NCI Item	Variable Name	Responses	Coding
Who decides your daily schedule? Who decides what you do in your free time?	Daily Schedule Choices Free Time Choices	2 - Person decides 3 - Person has help deciding 1 - Someone else decides 99 - Don't know, no response, unclear response	2 = 2 Person decides 3 = 1 Person has help deciding 1 = 0 Someone else decides 99 = not included
Do you choose what you do with your spending money?	Spending Money Choices	2 - Person chooses 3 - Person has help choosing what to buy, or has set limits 1 - Someone else chooses 99 - Don't know, no response, unclear response	2 = 2 Person chooses 3 = 1 Person has help choosing 1 = 0 Someone else chooses 99 = not included
Can you go on a date if you want to?	Dating Choices	98 - Does not want to date 2 – Yes, can date, or is married or living with a partner 1 – Yes, but there are some restrictions or rules about dating 0 – No 99 – Don't know, no response, unclear response	98, 2 = 2 Yes 3 = 1 Yes with restrictions 1 = 0 No 99 = not included

Arc's Self-Determination Scale: Short Form – Adult Version. The Arc's Self Determination Scale (SDS; Wehmeyer & Kelchner, 1995a) was first developed for use with adolescents with intellectual and developmental disabilities. The adult version of the SDS was developed by Wehmeyer and Kelchner through a straight forward adaptation of rewording items to be more appropriate for adult use (e.g., replacing *school* with *work)* (1995b). Both the adolescent and adult SDS have been adapted into short versions resulting in the SDS Short Form Adolescent version (Wehmeyer, Palmer, Shogren, & Seong, 2014) and the SDS Short Form adult version (hereafter referred to as the SDS-SFA) was utilized in the current study. The current study is piloting the SDS-SFA.

Similar to all other short form versions of the SDS, the SDS-SFA consists of 28 items and four domains: autonomy, self-regulation, psychological empowerment, and self-realization (Wehmeyer et al., 2015). Scoring for the SDS-SFA includes subscales scores and a total self-determination score, ranging from 0-49, with higher scores indicating higher levels of the construct measured. The SDS has adequate internal consistency construct (α= .92)(Wehmeyer & Bolding, 1999). In this study Cronbach's alpha was used as an indicator of reliability of the SDS-SFA scale (α= .742). Due to lower Cronbach's alpha in some of the subscales, the total score was used in the analyses (see subscales' Cronbach's alpha below).

Autonomy. The autonomy domain contains seven self-reported items on a 4-point Likert scale (Example item: *I plan weekend activities that I like to do*. Responses: 0 = "*I do not even if I have the chance*," 1 = "*I do sometimes when I have the chance*," 2 = "*I do most of the time I have the chance,*" 3 = "*I do every time I have the chance*") with a maximum total of 21. In this study Cronbach's Alpha was used as an indicator of reliability of the autonomy domain (α= .654)

Self-regulation. The Self-Regulation domain is comprised of two sections where the individual dictates his/her response to a scenario. Section I is comprised of six story-based items where the individual states what he or she believes to be the best solution for the problem presented in the story (e.g., *Beginning- Your friends are acting like they are mad at you. You are upset about this. Middle- recorded response. Ending- The story ends with you and your friends getting along just fine*). The responses of the individual are scored on a scale of 0 to 2 with a maximum total of 12.

Section II of the Self-Regulation domain asks individuals to identify a transportation goal and provide steps they need to follow in order to achieve this goal (e.g., *what type of transportation do you plan to use in five years?*). Scores for this section are accumulated based on the presence of a goal given and the number of steps given to reach this goal. In this study Cronbach's Alpha was used as an indicator of reliability of the Self-regulation subscale (α= .725).

Self-regulation items were scored by a graduate research assistant working on the OK-NCI project. Scoring was audited by the OK-NCI project coordinator. Discrepancies were reviewed by the project coordinator and the project PI and an agreement was reached on any inconsistencies in scoring.

Psychological empowerment. The Psychological Empowerment domain is comprised of seven self-reported items asking individuals to choose between two statements regarding which describes them better (Example item: *I have the ability to do the job I want or I cannot do what it takes to do the job I want.*) The maximum total for this section is 7. In this study Cronbach's

Alpha was used as an indicator of reliability of the Psychological Empowerment subscale (α= .722)

Self-realization. The last section in the SDS-SFA measures self-awareness and self-knowledge with seven statements (e.g., *I am confident in my abilities*) to which the individual responds with "yes it describes me" or "no it doesn't describe me." The maximum total for this section is 7. In this study Cronbach's Alpha was used as an indicator of reliability of the autonomy domain (α= .607)

Caregiver surveys. As part of the larger study and in order to gain a more comprehensive understanding of individuals with IDD that are receiving services in Oklahoma, Caregiver surveys were utilized to assess family members' and DSPs' experiences as caregivers. The *caregiver relationship* variable was gathered from the background information of the caregiver questionnaire. Possible relationship options included: Habilitation Training Specialist, Agency Companion, Foster Parent, Guardian, Parent, Sibling, Health Care Coordinator, House Manager, and Other. The caregiver was asked to mark all that apply to his or her situation. These caregiver categories were further reduced to two groups of either a DSP or a familial caregiver relationship. If the caregiver was both a paid DSP and a family member of the individual, then he or she was categorized as a family caregiver. Foster parents and agency companions were categorized as a family caregiver because of the length of relationships.

Data Analysis

First, descriptive statistics were computed for the variables and are presented in Table 4. For research question one, a series of bivariate correlations was computed to examine the

relations between the self-determination and of social-determination. For research question two, a series of regression analyses was computed to determine if caregiver relationship (Family & DSP) was a significant predictor of social determination variables. For research question three, four mediation regression paths using analytic framework for a single mediator were used to test for direct and indirect effects of caregiver relationships on social determination variables. Evidence of mediation if a significant indirect effect was found.

CHAPTER IV

FINDINGS

Preliminary Analysis

Preliminary analyses were run in order to prepare the data for the analyses needed to answer the research questions. Prior to analysis, the current study considered using residential setting as a predictor variable; however, due to collinearity caregiver relationship was chosen as the sole predictor variable within the regression analysis. Self-determination domains were standardized by obtaining z-scores in order to more accurately compare between domains. Since three of the items for social determination are in Section Two of the ACS, which can be answered by the individual, by a proxy (e.g., staff or family/friend), or with help from a proxy, descriptives were run to determine respondents for the following variables with the following results: daily schedule choices : 69.4% individual, 4.7% family/friend, 25.9% staff, free time choices: 74.1% individual, 3.6% family/friend, 22.3% staff, spending money choices: 73.6% individual, 3.6% family/friend, 21.8% staff. These results show that the individuals were the primary respondents for social determination questions in Section Two.

Bivariate Correlations

Self-determination total and subscales (autonomy, self-regulation, psychological empowerment, and self-realization) and social determination variables (dating choices, spending money choices, free time choices, daily schedule choices) were analyzed using Pearson product-

moment correlation coefficients in order to better understand the relations between the variables. Complete results of the bivariate correlations are presented in Table 5.

Hypothesis 1. Self-determination and social determination will be positively and significantly related. Results show that self-determination was positively and significantly correlated with dating choices, r (165) = .296, $p < .001$. Results show that autonomy was positively and significantly correlated with dating choices, r (169) = .295, $p < .001$. Results show that psychological empowerment was positively and significantly correlated with dating choices, r (155) = .231, $p = .004$. Results show that self-realization was positively and significantly correlated with dating choices, r (163) = .234, $p = .002$. However, self-determination was not significantly correlated with spending money choices (r (166) = .007, $p = .927$, *ns*), daily schedule choices (r (168) = .039, $p = .615$, *ns*), and free time choices (r (167) = -.021, $p = .789$, *ns*). Thus, hypothesis 1 was partially supported. Plausible reasons for these findings are discussed below.

Linear Regression

Four separate linear regression analyses were used to test if caregiver relationship predicts social determination variables: dating choices, spending money choices, free time choices, daily schedule choices. The results of the first regression analysis, dating choices on caregiver relationship, indicate that caregiver relationship accounted for 12.5% of the total variance in dating choices with marginal significance, $R^2 = .016$, (R^2 adjusted = .010), F (1, 185) = 2.935, $p = .088$. These results indicate having a DSP as a primary caregivers marginally predicts if the individual can go on a date if he/she wants. Results of the second regression analysis, examining spending money choices on caregiver relationship, indicate that caregiver

relationships accounted for 9.2% of the total variance in spending money choices, $R^2 = .008$, (R^2 adjusted = .003), $F(1, 189) = 1.604$, $p = .207$, *ns*. Meaning that caregiver relationship does not predict if the individual chooses what he/she buys. The results of the third regression analysis, examining daily schedule choices on caregiver relationship, indicate that caregiver relationship accounted for 9.4% of the total variance in daily schedule choices, $R^2 = .009$, (R^2 adjusted = .004), $F(1, 191) = 1.717$, $p = .192$, *ns*. Meaning that caregiver relationship does not predict if the individual decides his/her daily schedule. The results of the fourth regression analysis, examining free time choices on caregiver relationship, indicate that caregiver relationship accounted for 2.3% of the total variance in free time choices, $R^2 = .001$, (R^2 adjusted = -.005), $F(1, 190) = 0.097$, $p = .756$, *ns*. These results indicate that caregiver relationship does not predict if the individual decides what he/she does in his/her free time. Complete results of all linear regressions presented in Table 6.

Hypothesis 2. Individuals whose primary caregivers are DSPs will predict the opportunity to make choices regarding dating and will be more likely to decide what they purchase with spending money. Results show that caregiver relationship was not a significant predictor of dating choices ($b = -.265$, $p = .088$) or spending money choices ($b = -.116$, $p = .207$). Thus, hypothesis 2 was not supported.

Hypothesis 3. Individuals whose primary caregivers are family members will predict what they do in free time and during their daily schedule. Results show that caregiver relationship was not a significant predictor of daily schedule choices ($b = -.182$, $p = .192$) and free time choices ($b = -.029$, $p = .756$). Thus, hypothesis 3 was not supported.

Mediation Regression

Four mediation regression paths using analytic framework for a single mediator were used to test for direct and indirect effects of caregiver relationships on social determination variables: dating choices, spending money choices, free time choices, daily schedule choices. Each path, total effect, direct effect, and indirect effect were examined in the analyses.

The results of the first analyses, examining the mediating effect of self-determination on the relationship between caregiver relationship and dating choices, showed a total effect of *B* = -.296. This effect explained 15.08% of the variance on dating choices, R^2 = .0227, *F* (2, 165) = 3.839, *p* = .052, approaching significance. The direct indicates that caregiver relationship significantly predicts dating choices, *b* = -.297, *t* (165) = -2.056, *p* = .041. Note the results are slightly different when self-determination is present, this is due to the smaller sample for this analysis, due to the inclusion of self-determination as a mediating factor. These results indicate that individuals whose primary caregivers are DSPs influence the individual's dating choices. The indirect indicates that caregiver relationship does not indirectly, through self-determination, predict dating choices, *b* = .0011, Boot *SE* = .0521, 95% *CI* = -.1044, .1058. Meaning that an individual's self-determination does not explain the relationship between caregiver relationship and the individual's dating choices. Direct paths of the first mediation regression analyses is in Figure 2.

The results of the second analyses, examining the mediating effect of self-determination on the relationship between caregiver relationship and spending money choices, showed a total effect of *B* = -.128. This effect explained 10.21% of the variance on spending money choices, R^2 = .0104, *F* (2, 166) = 1.7476, p = .188, *ns*. The direct effect indicates that caregiver relationship does not predict spending money choices, *b* = -.128, *t* (166) = -1.382, *p* = .189. The indirect effect

indicates that caregiver relationship does not indirectly, through self-determination, predict the individual's spending money choices, *b* = .000, Boot *SE* = .011, 95% *CI* = -.025, .025. These results indicate that an individual's self-determination does not explain the relationship between caregiver relationship and if the individual chooses what he/she buys. Direct paths of the second mediation regression analyses were not displayed in a figure due to insignificance.

The results of the third analyses, examining the mediating effect of self-determination on the relationship between caregiver relationship and free time choices, showed a total effect of *B* = -.053. This effect explained 3.9% of the variance on free time choices, R^2 = .002, *F* (2, 167) = 0.255, *p* = .615, *ns*. The direct effect indicates that caregiver relationship does not predict free time choices, *b* = -.051, *t* (167) = -0.490, *p* = .625. The indirect effect indicates that caregiver relationship does not indirectly, through self-determination, predict free time choices, *b* = -.001, Boot *SE* = .008, 95% *CI* = -.030, .009. Meaning that an individual's self-determination does not explain the relationship between caregiver relationship and if the individual chooses what he/she does during free time. Direct paths of the third mediation regression analyses were not displayed in a figure due to insignificance.

The results of the fourth analysis, examining the mediating effect of self-determination on the relationship between caregiver relationship and daily schedule choices, showed a total effect of *B* = -.182. This effect explained 9.38% of the variance on daily schedule choices, R^2 = .009, *F* (2, 168) = 1.493, *p* = .224, *ns*. The direct effect indicates that caregiver relationship does not predict daily schedule choices, *b* = -.182, *t* (168) = -1.22, *p* = .224. The indirect effect indicates that caregiver relationship does not indirectly, through self-determination, predict daily schedule choices, *b* = .000, Boot *SE* = .0162, 95% *CI* = -.031, .036. These results indicate that an

individual's self-determination does not explain the relationship between caregiver relationship and if the individual chooses daily schedule. Direct paths of the fourth mediation regression analyses were not displayed in a figure due to insignificance.

Hypothesis 4. Self-determination will account for the relation between caregiver relationship and social-determination. The indirect effect will be greater than the direct effect. Results show that self-determination did not mediate the relation between caregiver relationship and any of the social determination items (Individual items: dating choices, spending money choices, free time choices, daily schedule choices). Thus, hypothesis 4 was not supported.

Figure 2

Direct paths of dating choices on caregiver relationship mediated by self-determination

Table 4

Descriptive Statistics of all Variables

	N	Mean	SD
Caregiver Relationship	193	1.16	0.363
Autonomy	154	13.35	4.226
Self-Regulation	97	2.99	2.721
Psychological Empowerment	132	5.28	1.187
Self-Realization	150	6.27	1.139
Total Self-Determination	170	-0.019	0.715
Spending Money Choices	191	1.76	0.461
Free Time Choices	192	1.82	0.461
Daily Schedule Choices	193	1.49	0.701
Dating Choices	187	1.58	0.760

Table 5

Correlations

	1	2	3	4	5	6	7	8	9
1. Self-Determination	-								
2. Autonomy[1]	.609***	-							
3. Self-Regulation[1]	.620***	.046	-						
4. Psychological Empowerment[1]	.772***	.283***	.260**	-					
5. Self-Realization[1]	.744***	.164*	.255**	.499***	-				
6. Spending Money Choices	.007	-.030	-.064	.127	.063	-			
7. Free Time Choices	-.021	.053	-.002	-.074	.002	.123	-		
8. Daily Schedule Choices	.039	-.003	.114	.093	-.016	.214**	.300***	-	
9.Dating Choices	.296***	.295***	-.003	.231**	.234**	.162*	.005	.124	-

Note: ***p < .001, **p < .01, *p < .05, [1]Subscales have been standardized

Table 6
Linear Regressions

	b	SE	Sig.
Dating Choices on Caregiver Relationship		.	
Constant	1.888	.187	.000
Dating Choices	-.256	.155	.088
Free Time Choices on Caregiver Relationship			
Constant	1.851	.112	.000
Free Time Choices	-.029	.093	.756
Daily Schedule Choices on Caregiver Relationship			
Constant	1.697	.168	.000
Daily Schedule Choices	-.182	.139	.192
Spending Money Choices on Caregiver Relationship			
Constant	1.899	.111	.000
Spending Money Choices	-.116	.092	.207

CHAPTER V

CONCLUSION

Previous literature suggests that social determination and self-determination should be related since both concepts surround decision-making for adults with IDD (Mehling & Tassé, 2014; Mehling & Tassé, 2015; Shogren et al., 2015; Shogren 2016); however, the results of the current study show little relation between the concepts. Self-determination is significantly related to an individual's ability to go on a date if he/she wants. Previous research suggests that individual's primary caregivers may influence the individual's participation in the decision-making process (Saaltink, MacKinnon, Owen, & Tardif-Williams, 2012); however, the results of the current study show that caregiver relationship (Family & DSP) does not predict choices regarding free time, daily schedule, and spending money. Yet, the current study shows support for the caregiver relationship predicting dating choices. One explanation of this relation is that individuals whose primary caregiver is a family member may have fewer choices about dating than an individual whose primary caregiver is a DSP. These results corroborate with previous research surrounding the caregiver's perception of dating (Cuskelly & Bryde, 2004). This could be due to parents of individuals with IDD having more conservative views towards dating as well as being more protective (Cuskelly & Bryde, 2004).

The current study has unique findings that do not corroborate with previous research. The goal of the current study was to examine the relations between caregiver relationship, self-determination, and social-determination. The relations between these variables were examined

using Causal Agency as a lens (Shogren et al., 2015; Shogren, 2016). Previous literature suggests that social determination is a reliable construct (Mehling & Tassé, 2014; Mehling & Tassé, 2015), yet the current study did not find social determination as a reliable construct. Possible explanation for this include differences in the sample. Mehling and Tassé (2014; 2015) had a significantly larger sample of 1772 participants. Additionally, 50% of participants in Mehling and Tassé's studies had a ASD while only 4.1% had ASD in the current study. Further examination of the individual items within social determination show the majority of the items are not related with each other, which shows concern for social determination as a construct. This contradicts previous research over social determination being a reliable outcome variable (Mehling & Tassé, 2014; Mehling & Tassé, 2015). However, within social-determination, an individual item (Can you go on a date if you want?) was significantly related to an individual's self-determination, autonomy, psychological empowerment, and self-realization.

The current study is unique in that self-determination is an outcome variable due to the examination of the predictive relation of caregiver relationship on self-determination. Other studies have used self-determination as an outcome variable (Wehmeyer et al., 2012); however, they have not examined the influence of an individual's context, specifically caregiver relationship, on self-determination. Wehmeyer's study examined differences between intervention and control groups, where the intervention was a model of teaching the teachers used help students modify and regulate their behavior (2012). Results of Wehmeyer's study show support for significant differences between the intervention and control groups, indicating that teachers who are equipped with the model of teaching are more able to foster self-determination in their students (2012). Similar to Wehmeyer's study, the current study examined the caregiver

relationship and how this support influences an individual's self-determination. Yet, the current study found no significant relation between caregiver relationship and self-determination. Examining the context in which an individual lives is important because understanding the unique influence of the context will better equip caregivers in fostering self-determination; therefore, increasing quality of life. While there was no support for caregiver relationship predicting self-determination, future research should examine others predictors of contextual factors (i.e., residential setting) that might influence self-determination. Within the community there are a variety of non-familial residential settings (i.e., Daily Living Supports, Group Home Large, Group Home Small, Alternative Group Home, etc.) and examining the unique influence of each of these settings would be an interesting area of future research.

Among the strengths of the current study is the author's active participation in the data collection and secondary data analysis over the past four years. The author has also served as a DSP for the past three years. This combination of professional and personal involvement with IDD has given the author a unique perspective. Another strength of the current study is that it captures the caregiver and the individual's perspective through the use of multiple surveys. An additional strength is the piloting of the SDS-SFA; the SDS-SFA is a version of the prominently used SDS (Wehmeyer & Kelchner, 1995a), and within this study proved to be a reliable construct (α= .742). An additional strength of the current study is the prevalence of individuals who answered social determination items independently or with some assistance, even though these items are in Section Two of the ACS and thus could have been answered by a proxy respondent.

Despite these strengths, the study is limited by the internal validity of social-determination. The low reliability of social determination led to the examination of the individual

items of social determination rather than social determination as a whole. Future research might address this issue by reexamining the validity of the construction of social-determination. An additional limitation of the current study is the uneven sample with the majority of individuals having a DSP as his/her primary caregiver (n = 162), compared to family caregiver (n = 31). This sample is not representative of the IDD population as a whole because the majority of individuals live within the family home (Owen et al., 2016). Another possible limitation of the current study is the phrasing of the question "*Can you go on a date if you want to?*" This question was used to gather information pertaining to an individuals dating choices. This question is a limitation due to its hypothetical nature (i.e., if you want to). This is different from the other social determination items as it is more vague in nature. In other words, an individual may perceive that he/she can date, yet may not be engaged in dating activities.

Although one of the study's hypotheses received partial support, the current study did not find support for self-determination being related to social-determination. The only item from social determination that was related with self-determination was if the individuals can date if he/she wants. This brings concern to the other items of the social determination construct, as well as the need for future research examining the choice of dating or not. Another possible explanation of the lack of relation between self-determination and social determination is the context of the sample. The majority of the sample lived in a home shared with other individuals with IDD (DLS and group homes) and with shared DSPs, This living arrangement may mean individual decisions are influenced by housemates. For example, if an individual has a roommate and one staff member, then the individuals daily schedule choices must take his/her housemate into consideration. This limits the individual's options regarding free time and daily

schedule choices. In regards to spending money choices, most of the individuals have limited spending money, thus limiting choices by way of little to no opportunity. Individuals may be so accustomed to these living and staffing arrangements that it does not appear to them that their choices are limited. The only social determination item related to self-determination was dating choices. This social determination item is separate from the other three as an individual's context does not appear to limit his/her response. Another plausible explanation is an individual may have the option to date if he/she wants to, yet has not acted on this choice. Thus the option to date has not been limited by context.

Caregiver relationship type did not predict if an individual chooses what he/she buys, decides daily schedule, or decides free time. However, Caregiver relationship did predict if the individual can go on a date if he/she wants to. There was also no support for self-determination mediating the relationship between caregiver relationship and if the individual chooses what he/she buys, decides his/her daily schedule, and decides what he/she does in his/her free time. While both self-determination and caregiver relationship significantly predict if an individual can go on a date or not, caregiver relationship did not predict an individual's self-determination.

In conclusion, the current study used a Causal Agency lens to examine the relations between the caregiver relationship type, self-determination, and social determination of individuals with IDD in order to gain a better understanding of the predictive relation of caregiver relationship on social determination and the mediating effect of self-determination. The key finding of the current study is an individual's primary caregiver marginally predicts if the individual can go on a date if he/she wants to. Another important finding is that caregiver relationship does not predict an individual's self-determination. This is important to note because

individuals with IDD often receive support from a variety of formal and informal caregiving supports. Research surrounding self-determination, and what influences self-determination, is important due to the positive outcomes associated with self-determination. This is important because by gaining a better understanding of what influences self-determination; policy-makers, practitioners, and caregivers can help foster self-determination in order to help individuals achieve a higher quality of life.

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APPENDICES

Appendix A

"Hi, my name is _____. I'm from Oklahoma State University on behalf of OKDHS-DDS, and I'm here to ask you some questions about where you live, where you work, your friends and family, and the people who help you. By answering these questions, you are helping us figure out how people with developmental disabilities in Oklahoma are doing, and how to make supports and services better.

"This is not a test, and there are no right or wrong answers to these questions. If you don't understand a question, let me know and I'll try to explain it. It's okay if you don't know how to answer. Whatever answers you give, you will not get into trouble and no one will be mad at you. Nothing will change about your services because you answer or don't answer these questions.

"You don't have to answer any questions that you don't want to. Just tell me if you don't want to answer."

"I'd like to know your opinions, how you feel about things. Whatever you tell me will be kept private, so you can be honest. We will be reporting about your health and safety so if something we talk about worries us that you may not be safe, we will have to tell someone about it.

VITA

Drew Addison Egli

Candidate for the Degree of

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