



DISSERTATION APPROVED BY

June 17, 2021

---

Date

*Leah Georges*

---

Leah Georges, Ph.D., Chair

*James R. Martin Jr.*

---

James R. Martin, Jr., Ph.D., Committee Member

*Jennifer Moss Breen Kuzelka*

---

Jennifer Moss Breen Kuzelka, Ph.D., Director

*Gail M. Jensen*

---

Gail M. Jensen, Ph.D., Dean

THE RELATIONSHIP BETWEEN TYPE OF RESIDENCE AND  
COMMUNITY ENGAGEMENT AND FRIENDSHIP FOR INDIVIDUALS  
WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES  
IN THE STATE OF OHIO

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By

CANDICE PATRICE MARKLE

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A DISSERTATION IN PRACTICE

Submitted to the faculty of the Graduate School of Creighton University in Partial  
Fulfillment of the Requirements for the degree of Doctor of Education in  
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## ABSTRACT

This study reviews the current state of deinstitutionalization for individuals with intellectual and developmental disabilities (I/DD) in Ohio. Current policy within the state of Ohio encourages greater levels of deinstitutionalization for individuals with I/DD. The purpose of this exploratory quantitative study was to identify difference in community engagement and friendship for individuals with I/DD based on residence. I analyzed data from the National Core Indicators Study completed in Ohio to identify differences in community engagement and friendship for individuals residing in institutional versus community homes as well as those residing in family versus group homes. No significant differences were identified based on residence. However, although not significant, differences were identified regarding seeing one's friends as well as community engagement, both based on residence. Therefore, I propose a three-tiered solution. First, I recommend additional research regarding community engagement and friendship, including gathering residents' feelings of satisfaction, based on residence. Second, I propose gathering additional information from individuals residing with families as well as those family members related to seeing one's friends. Finally, I detail an action research community engagement pilot project to gather additional information to best inform future work in this area.

*Keywords:* individuals with intellectual and developmental disabilities (I/DD), deinstitutionalization, community inclusion, community engagement, friendship

## Dedication

This work is dedicated to my son, Jamison, and my wife, Amanda. Amanda and Jamison, your support and encouragement pushed me through this journey. You both make my world better every single day.

## Acknowledgements

I would like to acknowledge all those who developed and oversee the National Core Indicators Study. This study provides invaluable information that can be utilized to better the lives of individuals with intellectual and developmental disabilities. I would also like to acknowledge the Ohio State University Nisonger Center and the Ohio Department of Developmental Disabilities for the completion of the NCI Study in Ohio and access to the research to complete this dissertation in practice. I would like to thank Dr. Jim Martin, whose love and knowledge of statistics and support with this paper helped to make it a reality. Finally, I cannot give enough thanks to my dissertation chair, Dr. Leah Georges. This has been a long road, and she has empowered, supported, and assisted me with knowledge, patience, and encouragement throughout the entire journey.

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## CHAPTER ONE: OVERVIEW OF THE DISSERTATION IN PRACTICE PROBLEM

Historically, individuals with intellectual and developmental disabilities (I/DD) were housed in large, institutional settings. These facilities segregated individuals with I/DD and there was not a focus on integration with the community at large (Thorn et al., 2009). From 1967 through 1985, a significant period of social reform occurred and nearly half of those who had resided in institutions moved into homes in the community, with hopes of increased satisfaction in terms of their paid supports, friendships, and community involvement (Landesman & Butterfield, 1987). This process is known as deinstitutionalization. Deinstitutionalization of individuals with I/DD has continued in different forms throughout the years. However, researchers have found that increased support and well-being for individuals with I/DD has not necessarily been a clear and linear result of deinstitutionalization reform. For example, researchers have found individuals experienced initial increases in home and community satisfaction followed by continued low levels of satisfaction, after as little as one year residing in the community (Bigby, 2008; Chowdhury & Benson, 2011; Francis et al., 2014). These findings run counter to many stereotypes as institutionalization is often associated with a history of subpar care, abuse, and the loss of personal autonomy and rights (Ferleger, 2010; Gaughan, 2008; Rosenbaum, 2016).

Issues around funding and housing for individuals with I/DD are also complex. For example, Medicaid Waivers provide funding for individuals with I/DD in Ohio who choose to waive their right to reside in an institution and instead utilize the funding for staffing and other needed supports (i.e. transportation, day programming) in the community (Ohio Department of Developmental Disabilities, 2014). Historically within

the state of Ohio, once an individual with I/DD elected to reside in an institutional setting, Medicaid Waiver funding for residing in a home in a community was no longer available. Due to limited Medicaid Waiver funds that restricted Medicaid Waivers to individuals in emergent need of housing, once an individual chose to reside in an institution, and therefore had a safe and permanent home, that individual never had needs that rose to a level urgent enough to secure Medicaid Waiver funding for community living (Horvath & Kleiman, 2015). In other words, an individual could always access an institutional home, but once in that institution, could not then choose to utilize Medicaid Waiver funding instead. However, in 2016, Disability Rights Ohio (DRO), an organization that advocates for human, civil, and legal rights for people with I/DD, fought against that limitation, leading to increased opportunities for individuals to move out of institutional settings and into homes in the community (Frech, 2018). DRO's activism around housing parallels the assumption that life outside of an institution is more gratifying than life within. For this study, I analyzed state level data to determine if that assumption is true within Ohio.

Specifically, I employed a quantitative secondary analysis of existing survey data from the National Core Indicators (NCI) Study that was on file with the Ohio Department of Developmental Disabilities (DoDD) to better assess community engagement and friendship for individuals with I/DD by comparing those who reside in institutional settings versus those who reside in a home in the community. The NCI is a validated instrument developed by the Human Service Research Institute, a nonprofit organization that utilizes research and data to create lasting and person-driven processes (Human Services Research Institute, 2017). Information through the NCI was collected in 2016-

2017 from both individuals and guardians of individuals with I/DD and was administered by staff employed at the Nisonger Center at the Ohio State University. One of the roles of the Nisonger Center is to conduct research with a mission of improving the lives of individuals with developmental disabilities as well as their families (The Ohio State University: Nisonger Center, 2019). My research is specifically focused on community engagement and friendship as data related to these concepts were directly gathered as a part of the NCI Study. The assessment of community engagement and friendship will help inform leaders within the field of I/DD to improve community and social inclusion opportunities for individuals with I/DD.

### **Statement of the Problem**

Deinstitutionalization largely began with the *Olmstead v. L.C.* (1999) United States Supreme Court decision that determined that if treating professionals deem someone can be accommodated in a community-based home, that individual has the right to reside in the community (Weber, 2004). Part of this decision was based on opinions that suggested individuals experience greater personal freedom and community inclusion opportunities outside of institutional living. However, Chowdhury and Benson (2011) assert that deinstitutionalization does not always lead to an automatic increase in general life satisfaction for all individuals.

Beginning in 2016, residents of Ohio with I/DD residing in institutional settings were provided the opportunity to move into community homes (Horvath & Kleiman, 2015). This option arose when DRO brought a class action lawsuit (*Ball v. Kasich*, 2016) on behalf of six plaintiffs and the Ability Center of Greater Toledo against developmental disability state officials, including the governor at the time, John Kasich (Disability



Rights Ohio, 2019). DRO filed the lawsuit based on the Americans with Disabilities Act premise that individuals with I/DD are entitled to receive care in a home where they can fully be a part of their larger community. DRO was able to show that individuals with I/DD already had the option of and right to institutional living, but the process to move into a home in the community was either too lengthy (a wait of years or decades) or not possible (those who had elected to move into an institution were then not able to ever receive Medicaid Waiver funding to move into a home in the community). The possibility of the class action lawsuit resulted in proactive actions from the Ohio DoDD, specifically by the Strategic Planning Leadership Group, which increased the number of non-emergent community funding (Medicaid Waiver) slots for individuals with I/DD (Horvath & Kleiman, 2015). Some of these slots were for individuals currently residing in institutional settings and others were to provide funding for individuals with I/DD who were on the waiting list for greater support funding (i.e., individuals residing with family or friends as natural supports in need of funding to live more independent lives). This opportunity prompted a second wave of deinstitutionalization throughout the state of Ohio. However, this movement and opportunity begs the question of whether non-institutional homes offer greater overall life satisfaction for individuals with I/DD, as previous lawmakers, some scholars, and advocates had believed to be the case. This study and its subsequent outcomes result in data-driven recommendations for the best possible support and options for individuals with I/DD.

### **Purpose of the Study**

The purpose of this exploratory quantitative study was to identify differences in community engagement and friendship for individuals with I/DD and/or their chosen proxy based on residence, institutional home versus a home in the community, within the state of Ohio. Specifically, I compared ratings of community engagement and friendship for Ohio residents who resided in institutional settings versus those who resided in homes in the community, as reported in the 2017-2018 NCI Study. NCI study data was gathered in person and from mail surveys from 766 individuals or a chosen proxy in the state of Ohio from 2017-2018 (National Core Indicators, 2017-2018a).

### **Research Question**

This study sought to answer the following research question: How do ratings of community engagement and friendship vary based on residential location (community home versus institution) for individuals with I/DD within the state of Ohio?

### **Aim of the Study**

The aim of this study was to use findings from this study, as well as previous research, to develop recommendations for leaders in the I/DD field in Ohio to increase community engagement and friendship for individuals with I/DD, based on residence.

### **Methodology of the Study**

This quantitative secondary analysis of existing survey data assessed existing data from individuals with I/DD and guardians of individuals with I/DD regarding community engagement and friendship. Throughout Ohio, between 2017-2018, 766 individuals were surveyed through the NCI study (National Core Indicators, 2017-2018). I analyzed existing data from the NCI study to identify differences in community engagement and

friendship based on residence: community or institutional home. As an exploratory study, I did not present hypotheses, and instead tested several logical relationships from the existing survey data.

### **Definition of Relevant Terms**

Operational definitions are provided as follows, to provide a clearer understanding of terminology within this study:

*Community home:* A home where an individual with I/DD resides with three or fewer other individuals with I/DD (unless it is a licensed home, in which an individual may reside with up to 7 other individuals), and where there are opportunities regarding choice and community inclusion (i.e., choosing meals within the home; support services can be chosen independently of one another, including employment or day programming, transportation, activities, etc.) (Ohio Department of Developmental Disabilities, 2019).

*Community engagement:* The act of active participation in an activity within one's community. Community engagement goes beyond simply being present in a community space. However, engagement does not necessarily equate to inclusion, as one could engage with others but still not be fully welcomed or included in that community activity.

*Community inclusion:* The process of being and feeling included within one's community activities, events, and public spaces. Imagine a person or group being both invited to an event as well as being incorporated within the larger group and fully immersed in the activities. Although some researchers have used the terms "community inclusion" and "community integration" interchangeably this study will reference "community inclusion" as it takes the process of being integrated, or physically present,

in a community setting one step further and denotes becoming a part of that setting. This practice is distinct from community integration, for purposes of this study.

*Community integration:* The practice of being physically present for one's community activities, events, and public spaces, but not being fully included within the larger group or not actively engaging in the activities within that space. Please note that some researchers have used the terms "community inclusion" and "community integration" interchangeably (Heller et al., 1998; Rosenbaum, 2016; Verdonschot et al., 2009; Vine & Hamilton, 2005).

*Deinstitutionalization:* The movement of individuals with I/DD out of institutional homes into homes within the community (Weber, 2004).

*Guardian of an individual with I/DD:* A guardian is a formally court-appointed guardian who is in place based on an individual with I/DD's cognitive limitations.

*Group home:* For the purposes of this study, a group home is an institutional or community home in which individuals with developmental disabilities reside.

*Individual with an intellectual or developmental disability (I/DD):* An individual who has been determined eligible for services through a local county board of developmental disabilities in the state of Ohio. Eligibility is determined based on an individual needing support in at least three out of nine activities of daily living as well as a qualifying I/DD diagnosis (Ohio Department of Developmental Disabilities, 2019).

*Institution:* A setting where an individual with I/DD resides with five or more other individuals, and where there are limitations regarding overall choice and community inclusion (i.e., meals are pre-determined with menus; all support services are

typically provided from the provider of the institution including day programming, transportation, activities, etc.) (Ohio Department of Developmental Disabilities, 2019).

*Medicaid Waiver funding:* Medicaid funding for individuals with I/DD who waive their right to reside in an institutional home, instead opting for a Medicaid Waiver to cover the financial portion of supports such as staffing within their home, transportation, and day programming (Ohio Department of Developmental Disabilities, 2014).

### **Limitations, Delimitations, and Personal Biases**

There are multiple limitations within this study. Initially, I hoped to collect data on life satisfaction from study participants rather than utilize information from a pre-existing database. However, the Ohio DoDD felt that information already collected through random sampling as a part of the NCI study would be able to provide the desired information and for the purposes of this study, I agreed. However, questions asked as a part of the NCI Study did not directly assess life satisfaction. Therefore, I identified questions from the NCI Study that assessed community engagement and friendship as those constructs, per my literature review, are correlated with life satisfaction.

Information was collected both from individuals with I/DD as well as some chosen proxy (guardian, advocate, staff) of individuals with I/DD. It should be noted that a chosen proxy's view may not be fully representative of the opinion of the individual with I/DD. Unfortunately, research specifically with individuals with I/DD, rather than guardians, advocates, or staff supports, is limited due to the vulnerable status of individuals with I/DD. Nonetheless, chosen proxy of individuals with I/DD are intimately involved with assisting such individuals to make life decisions, including where the individual chooses to reside.

As this data is from 2017-2018, it is already slightly dated. It would be beneficial to compare findings from this study with the most current Ohio NCI study data.

Additionally, the 766 participants that took part in the 2017-2018 NCI Study (National Core Indicators, 2017-2018a) had previously gone through a process of eligibility for I/DD services with their local county board of developmental disabilities in the state of Ohio. Therefore, this research is not representative of individuals with I/DD who have not sought additional I/DD support or assistance or gone through the eligibility process for such through their local county board of developmental disabilities. Wilhite and Sheldon (1997) noted that, in general, any research regarding individuals with I/DD that has been conducted has been with individuals receiving supports rather than those who are not, which lends to a positive bias. In other words, individuals with I/DD who do not receive support, even though they have a need for support, are excluded from most satisfaction surveys. Finally, an additional limitation is that I did not have any input into the development or phrasing of the questions that were asked as a part of the survey and received the findings as they were collected for the 2017-2018 NCI Study in Ohio.

As I chose to only focus on the Ohio NCI study, this is a specific delimitation as findings may not be representative of those in other states. Nonetheless, the existing database from which individuals and guardians were selected as a part of this survey is a thorough representation of individuals with I/DD throughout Ohio. Additionally, my initial intention was to gather both quantitative and qualitative data from individuals with I/DD who had moved into homes in the community from institutional settings over the previous three years and assess their satisfaction in terms of community inclusion versus a control group of individuals with I/DD who continued to reside in institutional settings.

While community engagement is assessed as a part of this research study, the data being utilized was collected for a broader purpose and is, therefore, not able to provide any specific qualitative information regarding satisfaction based on type of residence in the state of Ohio. In other words, the survey data for this study has a temporal significance in that it provides a snapshot of community engagement and friendship related to residence in the moment. Any individual differences between previous home or institutionalized settings were not analyzed in this study.

Personal biases are an additional area that need to be acknowledged regarding this research study. I have worked within the field of developmental disabilities for over a decade and currently work as the Housing Coordinator for the Cuyahoga County Board of Developmental Disabilities (Cuyahoga DD). To limit any potential bias, DoDD did not release the county of residence for individuals that were a part of the NCI study, but rather noted that the individual lived in a micropolitan, metropolitan, rural, or small town, based on zip-code. This additional limitation to disclosure helped eliminate any potential bias and the possibility of identifying a specific individual or guardian. Further, all other potential identifying information was removed from the data by DoDD prior to receiving it. As I work within this field, specifically within the area of housing, I cannot help but form opinions regarding institutions, deinstitutionalization, community homes, and community inclusion. I consulted with colleagues within and outside of the field of I/DD throughout the development of this study and subsequent data analysis to minimize bias as much as possible.

### **The Role of Leadership in this Study**

Leaders within the field of I/DD cannot promote positive change and increased opportunities for community inclusion for individuals with I/DD without data-driven findings regarding community engagement and friendship. This study provides leaders with current information for individuals with I/DD who reside in institutional versus community homes. Leaders within the field can then utilize this information to promote increased opportunities and options for this population of individuals.

### **Significance of the Dissertation in Practice Study**

Even though there has continued to be a push for more individuals with I/DD to live in community homes based on greater choice and perceived satisfaction in terms of home, friendships, and community engagement, some research has noted that there is not a significant difference in those areas based on institutional versus community residence (Bigby, 2008; Chowdhury & Benson, 2011; Francis et al., 2014). This study assessed if there are differences in community engagement and friendship based on residence.

This research is timely since a new wave of deinstitutionalization recently began in the state of Ohio; there is currently no other available research on the topic at hand specific to the state of Ohio. The current opportunity for individuals to move from institutions to community homes may have begun in 2016 but is still an available option for individuals with I/DD. Key goals related to the deinstitutionalization movement include increased satisfaction in the areas of friendships and community engagement and inclusion. Therefore, information gathered from this research will be able to immediately assist leaders within the field of I/DD in Ohio to improve related opportunities.



### **Summary**

In conclusion, this study assessed pre-existing survey data from individuals and guardians of individuals with I/DD regarding community engagement and friendship. Analyses determined what differences existed in those areas based on institutional or community residence. This information will help better inform leaders within the field of I/DD in Ohio to provide better options and opportunities for individuals with I/DD. In Chapter 2, I will provide an overview of the literature and research regarding deinstitutionalization, community engagement and inclusion, friendship, and residential options and differences for individuals with I/DD.

## CHAPTER TWO: LITERATURE REVIEW

Following the first wave of movement from institutions to homes in the community for individuals with I/DD in the 1970s-1980s, researchers studied the overall life satisfaction for those who moved (Heller et al., 1998; Larson et al., 2012b). Landesman and Butterfield (1987) concisely identified the benefits and challenges of institutional versus community living:

Proponents of deinstitutionalization and normalization recognize that community placement involves risk and raises complex questions about how to promote true social inclusion...Opponents stress the need of many who are mentally retarded to have protective, caring, and cheerful environments and to receive technically sophisticated training and health support systems prior to community placement...almost all would agree that minimally restrictive community living is a highly desirable *goal* for most citizens with mental retardation. As goals, normalization and deinstitutionalization are not terribly controversial; as *means* to achieving these goals, many of the current *practices* related to deinstitutionalization and normalization are. (p. 809)

These concerns, specifically how best to achieve deinstitutionalization and normalization for individuals with I/DD, are questions that have been explored for over four decades and are still being examined by researchers today. Therefore, while deinstitutionalization encompasses the goal of increased community inclusion, whether inclusion and normalization are realized will be further examined through this literature review.

More specifically, the following literature review will present findings on quality of life, friendship, and barriers to community engagement and inclusion for individuals

with I/DD residing in institutional settings versus those living in homes in the community or with their family. While these studies have been conducted throughout the United States and internationally, no studies have yet examined whether these ideals and goals have been achieved for individuals with I/DD who reside in homes in the community versus institutions within the state of Ohio.

### **Deinstitutionalization of Individuals with I/DD**

As of early 2021, there were multiple types of housing opportunities for individuals with I/DD. People could reside in homes with family members or friends, independently in their own home, in a home with other individuals with I/DD, or in larger institutional homes (Francis et al., 2014). Main determining factors regarding options for housing were the level of an individual's support needs and funding for those supports (in other words, the amount of staffing that is necessary and how those staff will be paid). Historically in Ohio, individuals with I/DD were able to move into an institutional home and all needed supports were provided within that environment, fully paid for through Medicaid. However, to live on their own, with family or friends, or in a smaller home in the community was not possible because no Medicaid Waiver funding was available for staffing supports within those non-institutional environments (Disability Rights Ohio, 2019). Nonetheless, both the first and second waves of deinstitutionalization provided an expansion of housing opportunities for individuals beyond institutions.

The deinstitutionalization movement for individuals with I/DD began in the early 1970s in the U.S. and resulted in more than a 50% reduction of individuals with I/DD residing in institutional homes (Lakin et al, 1990). Not only was there a reduction in institutions as residences overall, but there was also a dramatic decrease of the number of

individuals who reside in institutions that housed 16 or more individuals with I/DD.

According to Larson et al. (2012b), in 2010 only 56,813 individuals with I/DD lived in large institutional homes in the United States of America, down from 207,356 individuals in 1977. In other words, there was a significant decrease of individuals with I/DD residing in institutions that first began in the 1970s.

State finances regarding individuals with I/DD also showcase the deinstitutionalization trend during the 1970s. Morell (1979) emphasized the drastic increase in state spending for community services for individuals with I/DD that occurred between 1969 and 1976. For example, Morell detailed that in 1969 Alabama spent \$25,000 on community services, but in 1976 spent \$1.5 million in the same area. However, it should be noted that even with more money spent on community living, over time a shift away from institutionalization resulted in cost savings. Specifically, Murphy and Dattel (1976) predicted that in Virginia there would be an average cost savings of \$20,800 per individual over a ten-year period due to a move from an institutional home to one in the community. Taken together, this data suggests that although it was initially expensive to assist individuals to move into the community, there was an expectation of overall long-term cost savings. A review of recent institutional versus community living cost comparison research provides a more up-to-date understanding on how such costs are a part of the overall deinstitutionalization conversation.

Chou et al. (2008) conducted a research study in Taiwan that assessed a myriad of quality-of-life measures as well as costs based on residential setting. Three types of settings were included in the study: small residential homes where six or fewer individuals resided (25 settings), community homes with fewer than 50 individuals (35

settings), and governmental institutions where over 100 individuals with I/DD resided (20 settings). The researchers found a statistically significant difference in cost between small residential homes and institutional homes. Specifically, costs per resident were significantly lower in the small homes. It was noted, however, that there was considerable variation in cost within each of the service models. Additionally, the researchers discussed that only costs within the home were studied and while costs are significantly less within small residential homes, a much wider range of services and supports (i.e., nursing, therapies) are provided within institutional settings. Those supports are not covered within the cost of services provided for individuals within small residential homes, but the individual, family, and/or support staff are responsible for identifying those services outside of the home when necessary. Therefore, a more in-depth cost analysis is necessary to have a full understanding of whether institutional or community homes are truly more cost effective.

Despite the potential cost savings and assumption that deinstitutionalization lends to a greater quality of life, since the start of the deinstitutionalization movement, researchers have questioned whether moving people into the community results in those individuals achieving positive personal outcomes. For example, in their study that was published in 1987, Landesman and Butterfield noted that independent of residence (institution or community home), diverse treatment programs that excel in the care provided to the individual with I/DD have a great impact on quality of life. In other words, simply moving one into a home in the community does not necessarily better one's life experience. It will be critical for leaders within the field of I/DD to incorporate what Lowney (2003) referred to as love-driven leadership when working with individuals

with I/DD and considering the best possible housing opportunity. Leaders will need to consider individuals' desires, potential, and abilities to arrive at mutual agreement and collaboration to achieve a higher quality of life – whether those individuals reside in an institutional setting, a home within the community, or a family home. Additional review of the literature highlights findings about general quality of life for individuals with I/DD resulting from deinstitutionalization.

### **Deinstitutionalization and Quality of Life**

“The policy of deinstitutionalization was based on the proposition that quality of life of individuals with intellectual disabilities will improve as a result of being moved from institution to community-based care settings” (Chowdhury & Benson, 2011, p. 256). In fact, the National Council on Disability (2012), an independent federal agency within the United States focused on disability policy leadership, formally took a stance on deinstitutionalization in 2011 “that a smaller housing situation offers an opportunity for a higher quality of life” (p. 9). The current state of literature and research are summarized to more fully understand if quality of life has indeed improved through these supported deinstitutionalization efforts. The studies included in this section of focus specifically on quality of life within institutional settings versus quality of life following a move from an institutional setting into a home in the community.

### ***Family Perspective***

In a phenomenological study, Jones and Gallus (2016) interviewed family members of individuals who moved out of Oklahoma's last two state-run institutions when they were closed on July 10, 2015. Specifically, the researchers asked family

members about the process of deinstitutionalization as well as what factors influenced their perspective of the overall transition.

For the first phase of this study, through a direct postal service mailing through Oklahoma Department of Disability Services (DDS), 153 parents or siblings who were legal guardians of individuals with I/DD in the state of Oklahoma completed a quantitative, self-report survey. In the second phase, a convenience sample was recruited from participants in phase one and researchers that conducted qualitative, face-to-face, open-ended and semi-structured interviews with participants until theoretical saturation was achieved (no new data themes appeared to emerge). This resulted in a total of 23 family members being interviewed in a total of 19 separate interviews (four spousal units were interviewed together; those interviews were scored for themes as one participant).

The participants who were interviewed were full legal guardians of their loved one with I/DD and that loved one had transitioned from institutional living to residing in a home in the community for at least one full year to no more than three full years. The researchers identified 25 overall themes of desires of guardians for individuals with I/DD. Six of the most pronounced themes are as follows:

- a. respect our relative's history,
- b. collaborate – make us feel like we are a part of the process,
- c. provide quality care,
- d. provide consistent care,
- e. include my family member in the community,
- f. remember we are family. (p. 121)

Jones and Gallus also found that of those interviewed, 14 were initially opposed to the move to the community, but then voiced satisfaction regarding the move, while 5 participants remained opposed, mostly due to feeling a lack of success of community inclusion for their loved one in their new home. In their discussion on findings, Jones and Gallus highlighted that it is imperative that deinstitutionalization of an individual with I/DD be viewed not only as a transition for that individual, but rather as a transition for the whole family. Regarding overall quality of life for their loved ones, the interviewed guardians were interested in improvements in quality of care, greater choice in terms of home and community activities, and new possibilities for community engagement and inclusion. Multiple family members also noted a desire for increased opportunity for normative life experiences (i.e., going to the library, going shopping at the local mall, etc.). Jones and Gallus recommended that future research include longitudinal interviews to identify themes that occur over time as well as to include more from the perspective of the individual with I/DD.

### ***Life Satisfaction Based on Residence***

As Jones and Gallus (2016) identified, not all transitions into a home in the community are met with satisfaction. While Jones and Gallus followed individuals with I/DD who moved from an institution into a home in the community, other researchers have compared satisfaction based on residence. Lucas-Carrasco and Salvador-Carullo (2012) conducted a quantitative study with 99 individuals with I/DD in Catalonia, Spain utilizing the Satisfaction with Life Scale (SWLS; Diener et al., 1985). The researchers utilized convenience sampling to identify participants by contacting four agencies that provided supports for individuals with I/DD. Of the participants, 32 resided in a family



home, 33 lived in community homes with staffing supports, and 34 resided in institutional settings. All were able to provide individual consent to participate or consent was given by a guardian and the individual was found to be able to answer the battery of questions for the SWLS as well as questions from the World Health Organization Quality of Life scale. After analyzing the results, Lucas-Carrasco and Salvador-Carullo found that all participants self-rated positive satisfaction with life, and therefore there was not a significant difference in life satisfaction between those living in an institutional setting versus those living in the community. However, the researchers did identify that individuals with lower satisfaction with work and relationships scored slightly lower regarding overall life satisfaction than those with higher satisfaction within those areas. Therefore, residence alone did not solely affect life satisfaction. Rather, having opportunities to work and to build friendships should be considered independent of whether someone resides in an institutional or community residence.

### ***Behavioral Considerations***

While work and friendship satisfaction have been measured through self-report as independent measures that affect one's overall life satisfaction, researchers have also measured overall quality of life by assessing behavioral data. This type of analysis can be helpful due to the inability for some individuals with I/DD to verbalize satisfaction or concerns. Some researchers have assessed quality of life in relation to maladaptive or aggressive behaviors displayed by individuals with I/DD. For example, Larson et al. (2012b) conducted a meta-analysis in which they identified studies from 1977-2010 through searches on PSYCHINFO and ERIC databases, manual reviews of five I/DD scientific journals, manual reviews of reference lists, and the Google Scholar search

engine. Through their search, they identified and subsequently reviewed 265 different studies with a focus on deinstitutionalization and community for individuals with I/DD. A total of 38 studies were included in the meta-analysis, all of which assessed behavioral outcomes for individuals with I/DD. The selected studies either conducted longitudinal research (27) in which a group of individuals who had moved from an institutional home to a community home were followed over time and adaptive behavioral outcomes were assessed or contrast studies (11) in which both a group of individuals who had moved out of an institution along with a group who had remained within an institution were assessed regarding adaptive behavioral outcomes. Through these studies, the researchers looked at adaptive behavioral outcomes based on residential location.

Larson et al. (2012a) reported on data from the 11 contrast studies and found that in seven studies there was a statistically significant improvement in overall adaptive behavior for the group that had moved out of the institutional setting into community homes. Of the four studies for which there was not an identified statistical difference in adaptive behaviors, two reported better overall outcomes for those who left the institution and two reported better overall outcomes for those who stayed. The contrast studies also noted multiple statistically significant improvements for those who moved in terms of increased self-care and domestic skills.

The 27 longitudinal studies included within the meta-analysis collected baseline adaptive behavioral information before an individual moved out of an institution and then further assessed adaptive behavioral skills at least six months following a move into a home in the community. Of those studies, 15 reported statistically significant adaptive behavioral improvements, five reported improvements that were not statistically

significant, three reported a statistically significant decrease in adaptive behavioral skills, and two reported decreases that were not statistically significant. In considering both the contrast and longitudinal studies, the overall trend was a statistically significant increase in adaptive behavioral skills due to a move from an institution to a home in the community. However, it is important to note that of the 38 studies, 14 studies reported that there was not a statistically significant increase in adaptive behavioral skills based on residing in a community home and four studies even found decreased adaptive behavioral skills following a move from an institution into a community home. The trend of statistically significant adaptive behavioral changes based on residing in a community home for individuals with I/DD is noteworthy, but the number of studies that did not identify such results showcase that residing in the community does not automatically result in such a positive change.

Hamelin et al. (2011) conducted a meta-analysis that also assessed positive adaptive behavioral changes for individuals with I/DD based on a move from an institutional setting to a community home. They specifically reviewed 23 studies that assessed adaptive behavioral outcomes and quality of life for individuals with I/DD, with a focus on deinstitutionalization, through a search of three major databases (PsychARTICLES, SAGE Psychology Full-Text Collection, and PsychINFO) that originally yielded 351 articles. Of the 23 studies the authors ultimately included in the meta-analysis, a total of 10 independent variables were coded and included demographic information, methodological variables, and outcome variables. “The assessed domains of adaptive behaviour included a global score, self-care, communication skills, academic skills, social skills, physical development, community living, functional independence,

occupational skills, and cognition” (Hamelin et al., 2011, p. 65). Studies with participants across all levels of intellectual disability had more pronounced effects in comparison to studies that assessed only individuals with a severe or profound level of disability. The authors found that communication skills and physical development only had a slight increase in adaptive behavioral skills, but all other domains had a statistically significant, albeit moderate, increase in terms of adaptive behavioral skills based on deinstitutionalization. In other words, the researchers identified a trend that participants’ adaptive behavioral skills did increase based on deinstitutionalization.

In addition to an increase in adaptive behavioral skills based on deinstitutionalization, researchers have identified other specific variables that have been correlated to quality of life. For example, levels of stress and aggression were evaluated based on living environment to assess overall quality of life (Tamas et al., 2016). The researchers assessed a total of 122 individuals who lived in either institutions (51), at home with family (38), or in homes in the community (33). They utilized the Lifestress Inventory and Adult Scale of Hostility and Aggression Reactive-Proactive to conduct their research. The researchers found no significant difference of aggressive behavior between individuals residing with family or in an institution but did find a significant lower amount of aggression for those living in homes in the community. Additionally, the researchers found a significant correlation between aggression and experienced stress for individuals residing in institutions or at home with family (the correlation was not statistically significant for individuals residing in homes in the community). However, it should also be noted that the researchers admitted the possibility that individuals with lower amounts of stress and aggression may be the ones to have the opportunity to move

out of an institution or family home, while those with greater support needs may have been the ones to remain.

Whether considering family members' opinions on deinstitutionalization (Jones & Gallus, 2016), directly assessing the experience of individuals with I/DD (Lucas-Carrasco & Salvador-Carullo, 2012), looking at adaptive behavioral changes due to deinstitutionalization (Hamelin et al., 2011), or levels of stress and aggression based on living environment for individuals with I/DD (Tamas et al., 2016), the aforementioned researchers assessed overall quality of life for individuals with I/DD based on institutional versus community living. Overall, albeit with some exceptions, the findings suggest an increase or positive correlation with community living and quality of life, at times noted as a trend and other times statistically significant between groups. Limitations were noted regarding level of disability and who was able to reside in the community versus an institution. While the concept of quality of life is a key focus regarding the deinstitutionalization movement, it is beneficial to have a better understanding of what individuals with I/DD, as well as their loved ones, desire related to moving from an institution to a home in the community.

### **Quality of Life and Deinstitutionalization: A Closer Look at Related Variables**

The first wave of deinstitutionalization both decreased the number of institutions as well as the size of institutions (Larson et al., 2012a). Larson et al. noted that part of the desire for some individuals to move out of institutions was to reside with fewer people. Further, previous research has identified an increase in positive behavioral outcomes, both cross-group comparisons and longitudinally, for those who live in the community versus in an institutional setting. Francis et al. (2014) wanted to better understand why

research on deinstitutionalization tended to show an increased quality of life for individuals who moved into community homes. Through a literature review of 92 documents identified through GoogleScholar, WilsonWeb, Academic Search Premier, ProQuest, and inquiries to professionals in the field of housing for individuals with I/DD in the United States and the United Kingdom, the researchers investigated what specific variables within a home in the community contributed to increased quality of life outcomes. They identified four variables that influenced positive quality of life outcomes: residents, culture, staff, and the size of the home. Specifically, quality of life increased when individuals with I/DD were residing:

- with individuals with high adaptive behavioral skills and low challenging (aggressive or abusive) behaviors (residents),
- in a house that had characteristics of a more “normalized” home versus that of an institution with limited choice (culture),
- with staff that were knowledgeable, interactive, and exhibited high expectations of the individuals in the home (staff),
- and in a home with fewer individuals (three people or fewer in the home was found to have the greatest correlation with increased quality of life) and therefore more individualized supports (size of the home).

O’Brien et al. (2001) also conducted a qualitative study to identify specific outcome variables correlated with quality of life for individuals who moved from an institution to a community home in New Zealand based on a deinstitutionalization opportunity that occurred in 1988. Specifically, 61 people with I/DD moved from a psychiatric hospital to homes in the community. Nine years after the move, interviews

were held with the individuals with I/DD, staff, and family members for 54 individuals who were still residing in the community. The researchers identified the following positive outcomes for the individual with I/DD: acquisition of increased adaptive behavioral skills, a life with more variety, a life more normalized than was possible residing in an institution, and a home that they identified as their own (O'Brien et al., 2001). Quality of life is, overall, a broad concept, and the identification of more specific opportunities within one's life helps to better identify how one might have an improved quality of life in a specific residential setting. The need for leaders to be adaptable and flexible regarding what this might mean to each individual with I/DD is an ideal highlighted by Lowney (2003) who noted that a principle of heroic leadership includes promoting a culture of adaptability and change as needed.

Finally, Vine and Hamilton (2005) also looked at specific individual characteristics related to deinstitutionalization for 37 male individuals, all of whom had severe levels of I/DD, who moved from an institution to community homes. These men had all been institutionalized for 14 to 55 years and at the time of the study had been residing in homes in the community for four to five years. The variables of adaptive behavior (communication skills, daily living skills, and communication skills), maladaptive behavior, choice making, life circumstances (material well-being, physical well-being, residential well-being, access to one's community, daily routine, choice, and connection with family and friends), and quality of life were all assessed through validated assessment instruments. Vine and Hamilton only found a statistically significant association between adaptive behavior or life skills and life circumstances. In other words, the ability to make choices and put in place personal skills was associated

with a higher quality of life, but no other assessed variables were related with a higher quality of life. Vine and Hamilton posited that it is inappropriate to study quality of life as a broad construct, as it does not provide a full or accurate picture of whether specific outcomes have been achieved for individuals who move from an institution to a home in the community.

### **Community Engagement and Inclusion**

Researchers have specifically examined the multi-faceted variable of community engagement and inclusion related to deinstitutionalization of individuals with I/DD. For example, Salkever (2000) analyzed United States' survey data collected through the 1990 National Consumer Survey of People with Developmental Disabilities and Their Families to assess activity levels and life satisfaction of young adults with I/DD. The study examined different forms of activity, such as employment, education, and volunteer work, in which the individual engaged in his or her community. Salkever found that life satisfaction was lowest for individuals who had the lowest levels of engagement within their community. He also determined that paid employment, volunteer work, and education were all related to increased levels of life satisfaction with no statistically significant differences between the specific type of community engagement that was chosen by an individual.

Some researchers have examined the connection between one's level of adaptive functioning and one's engagement within their community. Heller et al. (1998) conducted a longitudinal study that examined institutional versus community settings in terms of adaptive functioning and community inclusion for individuals with I/DD. They operationalized adaptive functioning based on the Inventory for Client and Agency



Planning developed by Bruininks et al. (1986) as an individual with I/DD's ability to perform daily functions, including motor skills, social skills, communication, personal living skills, and community living skills. In total, 331 individuals were initially assessed, and three years later follow-up assessments were conducted on 201 individuals who had moved and 67 who remained in an institutional setting (the remaining individuals either passed away or consent was not given to gather follow-up data). Information was gathered through individual and staff interviews as well as multiple quantitative instruments. Heller et al. found a statistically significant relationship between the participants' age, adaptive behaviors, and community inclusion at baseline with community inclusion at follow-up. In other words, individuals who were younger, had higher abilities in terms of adaptive behavior, and who already were integrated into their community then had higher levels of community inclusion at follow-up. Additionally, individuals in community versus institutional homes had statistically significant higher levels of community inclusion at follow-up.

While Heller et al. studied community inclusion based on characteristics of individuals with I/DD, since the term community inclusion is quite broad, other researchers have further operationalized community inclusion by breaking community into smaller categories. There are multiple aspects of community engagement and inclusion that can be examined. For example, Verdonschot et al. (2009) conducted a meta-analysis on articles from 1996-2006 through the PubMed, CINAHL, and PSYCHINFO databases. They searched for community inclusion terminology in the areas of domestic life, relationships, and civic and social life and resulted with 23 papers after reviewing 2,936 initial matches. The studies that were included in the final meta-

analysis were either quantitative or other meta-analyses and the researchers determined that while individuals with I/DD who lived in community settings were more participatory in the community, all individuals with I/DD were significantly less engaged in their communities than individuals without a developmental disability. They also noted a lack in interpersonal relationships for individuals with I/DD, including both friendships and romantic relationships.

Verdonschot et al.'s (2009) finding of limited community inclusion and relationships for individuals with I/DD presents an area of opportunity for growth. Leaders within the field of I/DD can commit to working for the betterment of what is needed for and desired by individuals with I/DD. Such a position aligns with what Haslam et al. (2011) refer to as being an in-group champion. Specifically, Haslam et al. noted that a leader can achieve greater success if that leader takes it upon themselves to identify as a part of any group they are seeking to lead. If a leader within the field of I/DD were to follow this example, whether or not that leader identified as someone with I/DD, that leader could become a stronger advocate for individuals with I/DD as well as have a better chance of achieving success that made a difference for the whole group.

Cushing (2015), in a journal article in the *International Journal of Developmental Disabilities* acknowledged that the professional ideal of increasing community engagement for individuals with I/DD has been too vague in definition and has allowed for only a narrow understanding of how this can be achieved. She highlighted that research has often been conducted with staff or family members of individuals with I/DD and recommended gathering additional information from individuals with I/DD directly to better meet their unique needs and outcomes. She also urged professionals to consider

limitations to the idea of the achievement of community engagement and inclusion for individuals with I/DD purely through immersing them in with typical community, and urged leaders in the field to consider alternative community opportunities, including ones purely for individuals with I/DD. Regarding deinstitutionalization, it is not just a matter of individuals residing in homes within a community, but also setting people up with specific supports in order to realize true community engagement and inclusion.

Cummins and Lau (2003), in a review of current research literature focused on community inclusion for individuals with I/DD, identified the concern that multiple measurements focused on inclusion as simply being physically present in a location rather than being more fully engaged or included within community activities. They emphasized that while physical presence is a component of community inclusion, it does not necessarily lead to the successful outcome of a sense of community for the individual in question. They highlighted that well-being is connected to *social* connection and active participation, not just *physical* presence. Cummins and Lau made the practical recommendation that there is a need to go beyond physically going into the community to individually identify what community means to each unique person with I/DD. In other words, there is a difference in merely going somewhere in the community, such as a local coffee shop, and developing a rapport with others that are frequenting the shop and/or the baristas. One part of people feeling a sense of community is through the successful development of friendships, especially those outside of staff and family, which is another specific area of consideration regarding successful community engagement and inclusion.

Simplican et al. (2015), continued with the importance of social connection with a focus on social inclusion. They stated that there are multiple and conflicting theories of

inclusion, which makes policy development and improvement challenging. Due to these concerns, they then proposed there is a need for the development of a more universally agreed upon way to define social inclusion. They specifically proposed an ecological model be developed that included aspects in the realms of “individual, interpersonal, organizational, community, and socio-political” (p. 26). This proposal brings previously mentioned research findings full circle. The move from an institution alone does not necessarily improve one’s quality of life. Rather, specific areas of focus can lead to improved quality of life, and those areas, such as community or social inclusion, require universally agreed upon operational definitions to fully understand how to move forward in a meaningful way.

Just as operational definitions are critical, ensuring that all people involved within the process of deinstitutionalization are informed of desired personal outcomes to improve quality of life is imperative to the success for the people with I/DD who move into a community home. Clement and Bigby (2009) analyzed data collected from ethnographic and action research methods that assessed community inclusion of five men with severe to profound I/DD who had moved out of an institution to homes in the community in Victoria, Australia. Clement and Bigby emphasized the importance of staff being informed of inclusion outcomes and stated that unless staff are convinced of the benefits of community inclusion for all individuals with I/DD, many may not see the actualization of opportunities, especially regarding those with more severe or profound disability. If it is not known how to specifically improve upon one’s overall quality of life through identified personal outcomes, an increase in quality of life may not be possible. The ecological model proposed by Simplican et al. (2015) along with the importance of

full social inclusion beyond physical presence within one's community (Cummins & Lau, 2003) can further help staff and family members to fully assist individuals with I/DD to meet identified outcomes.

### **Friendship**

Increased and improved friendships are factors that those with I/DD as well as family members hope to see positively changed through a move from an institution to a home in the community. Multiple researchers have found a connection between friendships held by individuals with I/DD and quality of life. Lucas-Carrasco and Salvador-Carulla (2012) conducted a study with 99 participants with I/DD in Catalonia, Spain that assessed life satisfaction and quality of life through two different assessments. Satisfaction with life was assessed by self-reporting on a scale that looked at overall well-being while quality of life was assessed through four different domains of one's life (physical, psychological, social, and environment). While multiple variables were studied as a part of this research, one specific finding was that those with greater satisfaction regarding friendships were also found to have greater satisfaction in life.

Even when operationally defined, overall life satisfaction is a broad construct. Therefore, other researchers have taken a more pointed look at specific variables that correlate with friendship. For example, Friedman and Rizzolo (2018) conducted research by analyzing data from The Personal Outcomes Measures Questionnaire that had been taken by just under 1,300 individuals with I/DD. They found that strong friendships were correlated with improved outcomes in the following areas: safety, freedom from abuse and neglect, fair treatment, intimate relationships, self-advocacy, and greater community interaction and participation. This is noted as a correlation rather than causation because

they note that it is possible there is a cyclical effect in place. For instance, as individuals have an increase in the number of quality friendships they hold, they may then engage more in their community because they have more resources (friends) with which to do so. Greater participation in the community can then lead to an increased number of interactions with more people and lead to even greater friendships, both in terms of number and quality. Nonetheless, improved friendships connected with increases in almost every outcome area within a person's life.

Van Asselt-Goverts et al. (2015) conducted a study in the Netherlands with a total of 33 individuals with mild or borderline levels of I/DD who lived in homes in the community for at least two years. Individuals completed a variety of quantitative assessments that were then analyzed by the researchers. Like the findings of Friedman and Rizzolo, Van Asselt-Goverts et al. determined that social inclusion, including a network of social support (friends), contributed to increased quality of life for individuals with I/DD. However, they also determined that most individuals had closest friendships with family and paid supports rather than with friends made outside of those areas. Verdonschot et al. (2009) formed a similar conclusion through a meta-analysis and found that most of the friendships for individuals with I/DD were with others with I/DD or paid supports, and even family relationships were typically considerably limited in comparison with the general population. Van Asselt-Goverts et al. and Verdonschot et al. discussed that future research could focus on what, if any, differences or limitations exist based on the trend that friendships for those with I/DD are often limited to paid staff and family members. Overall, regarding friendship, researchers have highlighted the critical importance of friendships and found significant relationships between the quality and

quantity of friendships and life satisfaction for individuals with I/DD but have also found a substantial dearth in the number and diversity of friendships for individuals with I/DD outside of family or paid supports.

Despite limitations to the quantity or types of friendships that typically exist for individuals with I/DD, there is room for research regarding types of friendship, such as that of roommate or housemate relationships. Wiltz (2003) developed a Roommate Friendship Scale and tested the reliability and validity of the scale with pairs of individuals that were or had been housemates. The pairs of housemates (a total of 186 individuals with I/DD) were grouped into two categories: housemates that continued to reside with one another (114 individuals, “Compatible Dyads”) and housemates that no longer resided together due to conflict with one another (72 individuals, “Incompatible Dyads”). Wiltz developed the scale with the hope that other researchers would further explore compatibility and friendship components of housemates for individuals with I/DD. He was able to determine that incompatible dyads had significantly lower friendship scores than compatible dyads. Wiltz discussed that his results speak to the importance of greater care being given to individuals with I/DD residing together.

Also specifically pertaining to housemates, Francis et al. (2014) conducted a literature review of a total of 92 documents as well as conversations with experts that examined what specific variables within a household are related to quality-of-life outcomes. The researchers determined that quality of life was greatly impacted by the level of accord one had with one’s housemates. Specifically, they noted that an individual’s quality of life tended to significantly decrease if residing with a peer with I/DD that had significant behavioral support needs. As previously noted, Wiltz (2003)

reported that incompatible housemate dyads were filled with conflict and discord. It is not friendship alone that is critical in housemate pairings, but personality traits and behavioral tendencies that predict overall housemate success. Therefore, great care in pairing housemates to provide for maximum accord and less conflict is an important consideration regarding overall quality of life.

### **Barriers to Community Engagement and Inclusion**

Research has been conducted on community engagement and inclusion for individuals with I/DD not just because increased community inclusion is a specific objective connected to deinstitutionalization (Cottrell, 2005; Heller et al., 1998; Jones & Gallus, 2016), but also because community engagement has been shown to correlate directly with overall quality of life for individuals with I/DD (O'Brien et al., 2001; Salkever, 2000). Due to the broad construct and operationalization of 'community inclusion', researchers have studied different facets of community inclusion for individuals with I/DD. One specific area of study has focused on social inclusion, including the importance of friendships. Furthermore, Friedman and Rizzolo (2018), Van Asselt-Goverts et al. (2015), and Francis et al. (2014) all found positive relationships between individuals with I/DD having friends and overall quality of life. Therefore, community inclusion and friendship are key areas to consider when looking at overall quality of life regarding deinstitutionalization. However, there are multiple barriers to successful community inclusion that can limit overall community inclusion satisfaction for individuals with I/DD.



### *Community Acceptance*

One of the barriers to community inclusion is based on the level of (or lack of) acceptance by people in the community. Johnson (2015) noted that leaders have a moral imperative to work toward inclusion, especially for people typically excluded from group participation. Van Alphen et al. (2012) conducted a study through a nationwide internet panel in the Netherlands. A total of 426 adults answered questions about their feelings regarding individuals with I/DD moving in as their neighbor. The researchers varied the number of individuals moving into the home as well as the severity of the level of disability of the individuals that would be moving into the home to determine whether group size and/or level of disability (mild versus severe) led to greater or lower levels of overall acceptance. Van Alphen et al. found that research participants preferred homes with a smaller number of individuals with I/DD as well as individuals that had milder rather than more severe levels of I/DD. The researchers also found a significant correlation between emotional responses of anger and anxiety from research participants at the idea of contact with individuals with more severe levels of I/DD compared to the idea of contact with individuals with more mild levels of I/DD. Overall, a significant number of respondents also expressed annoyance and feeling burdened at the idea of individuals with severe I/DD moving into a home next to them.

Prior to the internet study, Van Alphen et al. (2010) conducted a formal research study with 30 people in 12 different neighborhoods in the Netherlands who lived next to individuals with I/DD. The researchers conducted semi-structured interviews based on a topic list that specifically delved into experiences and associated feelings related living next to individuals with I/DD. Some key themes emerged, including the following:

- Multiple research participants expressed a lack of being able to fully get to know neighbors with I/DD due to high turnover in the homes (people with I/DD moving in and out of homes without introductions or farewells).
- Participants in the study expressed that neighbors with I/DD did not participate as a part of the neighborhood (i.e., high fences, rarely coming out of their home, extreme privacy) or only spent time in groups with others with I/DD.
- Multiple participants expressed apprehension in interacting with neighbors with I/DD, even in simply engaging in small talk.
- Finally, those that were a part of the study expressed that they most often engaged directly with staff of individuals with I/DD rather than the individuals with I/DD.

Based on these findings, the researchers suggested that further information and education for people in the community who will be neighbors of individuals with I/DD would be helpful to combat concerns and encourage positive interactions. Alter (2009) postulated that leaders cultivating relationships may need to spend years putting forth such efforts and growing common goals and understanding. Therefore, leaders within the field of working with individuals with I/DD should expect that years of growing community relationships is necessary to attain success for individuals with I/DD moving into community homes. Building community connections is not just a benefit for individuals with I/DD, but for those already within the community as well.

### ***Community Participation***

Other researchers have also noted limitations regarding community inclusion for individuals with I/DD even when they move into homes in the community. Badia et al. (2011) utilized a convenience sample of adults with I/DD throughout diverse regions in

Spain. The researchers collected demographic information as well as data through the Spanish version of the Leisure Assessment Inventory to analyze data related to community participation, as well as constraints to participation, in different types of leisure activities. The researchers found individuals with I/DDs' perception of barriers to community engagement had a significant impact regarding activity participation. Specifically, regarding social activities, a lack of time, feeling too old, dependency on another person to participate in an activity, and the fear of being made fun of correlated with reduced engagement. Leaders within the field of I/DD can utilize information that has come directly from individuals with I/DD to implement options that overcome these shared perceptions. Rath and Conchie (2008) emphasized the importance of leaders being trustworthy. Within the field of I/DD, addressing sensitive concerns directly and consistently is one way that trust can be built. With trust, barriers can be broken down so community inclusion for individuals with I/DD can become more fully realized.

### ***Friendship***

The importance of friendships for individuals with I/DD in relation to community engagement and social inclusion was previously highlighted. Bigby (2008) conducted longitudinal research on relationships and social connectivity for individuals with I/DD following a move into the community. Bigby studied a group of 55 individuals with I/DD who resided in Melbourne, Australia and moved from a large institution to homes in the community. Data was collected through structured interviews prior to the individuals moving from the institution and at one, three, and five years following their move. Bigby's research found an overall decrease in the number of individuals with I/DD who remained in contact with family members at the five-year mark. Bigby also discussed that

even though building community networks was stated as an outcome for every individual with I/DD as a part of their transition into the community, at the three-year mark, only four individuals (17%) were formally engaged in this type of community building. Finally, throughout the study only one individual with I/DD identified a close friend outside of housemates, family, or staff. Bigby discussed that there was no evidence that any staff maintained a friendship with an individual with whom they worked after they discontinued working in a home. Therefore, individuals with I/DD did not build social networks within their community following a move into a community home. This lack of social networks led to multiple people with I/DD not having any connections within their community. Bigby highlighted that these findings mirrored studies conducted in both the United Kingdom and the United States that showcase the fact that physical presence (or a move into a community home) is not the same as being a part of one's community. This study represents the barriers to community inclusion that occur due to a lack of social network building for individuals with I/DD.

Overall, there is not a significant amount of research that has been conducted regarding barriers to community inclusion once individuals with I/DD have moved into a home in the community, and even less that provides recommendations on how to begin to overcome such limitations and barriers. However, the studies that have been conducted that touch upon these barriers provide critical information regarding how to increase community inclusion for individuals with I/DD. Leaders within in the field of I/DD can utilize such information to increase community inclusion opportunities. Authentic leadership is grounded in being transparent and responsive to needs within a community

of people (Northouse, 2013) and that type of leadership could be utilized effectively to increase opportunity for individuals with I/DD.

### **Deinstitutionalization in the State of Ohio**

One formalized barrier to community living for individuals with I/DD within the state of Ohio has been the opportunity to access the Medicaid Waiver funding necessary for staffing supports to reside in a home in the community rather than remain in an institution. As previously stated, a second wave of deinstitutionalization within the state of Ohio was made possible through additional Medicaid Waiver opportunities, known as Exit Waivers, that were provided through DoDD beginning in 2016 (Horvath & Kleiman, 2015). Exit Waivers are Medicaid Waivers that provide funding for staffing supports for individuals who were residing in an institution to move into a home in the community. The Exit Waiver opportunity was put in motion when DRO filed a lawsuit against the state of Ohio due to limited Medicaid Waiver opportunities and therefore community living options for individuals with I/DD (*Ball v. Kasich*, 2016).

On January 10, 2020, the Ohio DoDD and DRO filed a settlement agreement to bring a conclusion to the *Ball v. Kasich* (2016) lawsuit (Department of Developmental Disabilities, 2020). The final agreement included a statement from DoDD that individuals should not be forced to remain within an institutional home, but that individuals and their families or guardians should have choice to reside in a home in the community or an institutional home. Since 2016, DoDD worked to increase meeting needs of individuals with I/DD through Exit Waiver opportunities as well as to increase employment opportunities within the community, address identified needs of individuals with I/DD

and provide opportunities for people to have needs met outside of Medicaid Waiver funding, and decrease the size of institutional facilities (Frech, 2018).

Even though the research for this study was conducted through a survey completed in the state of Ohio, present-day deinstitutionalization for individuals with I/DD has been in process across the entire United States of America. For example, Oregon closed all institutional settings in 2007, becoming one of ten states and Washington D.C. to provide housing opportunities for all individuals with developmental disabilities within the community (National Council on Disability, 2012). The National Council on Disability noted that there are still states that offer limited funding opportunities for people with I/DD to live in community homes. They emphasized the importance of continued deinstitutionalization efforts in states that overwhelmingly provide housing for individuals with I/DD in large institutional settings. The results from this study can be utilized to inform those within the field of I/DD throughout the United States whether a state primarily offers funding for community homes, institutional housing, or a mix of both.

### **Leadership within the Field of I/DD**

In terms of informing those within the field of I/DD, Cushing (2015) noted the importance of leaders being open to new and creative ways to increase community engagement opportunities. To do this, she recommended gathering additional information directly from individuals with I/DD. Due to individuals with I/DD being a protected class/vulnerable population for the purposes of research, there are limited studies in which individuals with I/DD have been direct respondents. Rather, often guardians, advocates, or staff have answered on behalf of individuals with I/DD. However, data

from the NCI research study is from individuals with I/DD as well as a chosen proxy of these individuals. Therefore, the results of this study add often underrepresented voices to the available research.

Leadership within the field of I/DD is multi-faceted – from individuals with I/DD who are self-advocates, to staff who work with individuals with I/DD, to workers at county boards of I/DD and the Ohio DoDD, and finally to community members, family, and friends who take on roles of leadership and advocacy. Transformational leadership emphasizes true collaboration between leaders and followers as well as an understanding of the need for adaptation based on changing needs (Northouse, 2013). As more information is gained regarding desired residences for individuals with I/DD within the state of Ohio, those aspects of transformational leadership are critical to overall success. Haslam et al. (2011) emphasize that leaders who work within the realm of social identity leadership must focus on what that specific social group values and what they deem their “specific Eden” (p. 192). Therefore, desired outcomes regarding type of residence, community engagement, and friendship need to be gathered directly from individuals with I/DD. Additionally, as those who work with individuals with I/DD are often within a role of power and privilege, it is critical that leaders recognize what Johnson (2015) refers to as the shadow of privilege. Leaders often have greater privilege than followers, so must be careful to acknowledge the power imbalance and act in ways that best support others rather than to their own benefit.

Multiple researchers highlighted that community engagement and inclusion are critical for increased quality of life and often a larger factor than residence. To this point, Power (2013) noted that professionals within the field need to be thoughtful in

identifying and implementing ways for individuals with I/DD to truly become a part of their communities to thrive within them. He stated that this will not be achieved quickly but must remain a priority to improve overall outcomes and life satisfaction.

Additionally, it is critical for communities to be developed that welcome and fully include individuals with I/DD (National Council on Disability, 2012). Therefore, this study examined not just whether there was an increase of individuals residing in community homes over institutions (there was) but assessed community engagement and friendship to better determine if individuals within community homes were thriving.

### **Summary**

Beginning with deinstitutionalization in the 1970s and through today, advocates have sought after improved quality of life and improved community connections and inclusion for individuals with I/DD. While some research has identified higher quality of life outcomes for individuals residing in community homes over those residing in institutional settings, a large portion of the literature found a lack of significant difference in quality-of-life based on residence. Robison et al. (2011) summarized these findings by stating that a wide range of opportunities is best, so that individuals can identify what fits their personal needs and outcomes. Through their research, they found that individuals with I/DD residing in institutions as well as community homes both desired greater independence and surmised that beyond housing type it is critical that all homes provide engagement and opportunities for companionship. Despite a continual push for deinstitutionalization, there is a need to improve outcomes and quality of life for individuals with I/DD no matter where they reside. In Chapter 3, I detail the methodology for my secondary data analysis, from which the findings can be used to better inform



leaders in the field of I/DD to improve community engagement and friendship outcomes for all individuals with I/DD.

### CHAPTER THREE: PROJECT METHODOLOGY

The intent of this quantitative study was to identify ratings of community engagement and friendship for individuals with I/DD as well as determine if there were differences in those areas based on residence (institutional versus community home) within the state of Ohio. Specifically, this study employed a secondary analysis of existing survey data from the 2017-2018 Ohio NCI Study (National Core Indicators, 2017-2018a) to identify differences in community engagement and friendship based on residential location.

In the following chapter, I review the research question, provide an overview for the research design and secondary data analysis, discuss permissions granted for obtaining that data, and detail information specific to the 2017-2018 Ohio NCI Study. The information gained from the secondary data analysis can assist leaders within the field of I/DD and within the state of Ohio to better assist individuals with I/DD meet personal outcomes within the areas of community inclusion and friendship.

#### **Research Question**

This study sought to answer the following research question: How do ratings of community engagement and friendship vary based on residential location (community home versus institution) for individuals with I/DD within the state of Ohio?

#### **Research Design**

The data for this research was secured through an already completed study in the state of Ohio (NCI Study, 2017-2018a). I collected the data and presented descriptive statistics. I then analyzed the data by statistically testing a variety of relationships. This section provides detailed information on the study, how I obtained permissions to acquire

data from the study, details regarding NCI data collection, and information on other variables that may have influenced overall analysis.

### **National Core Indicators (NCI) Study**

The National Core Indicators (NCI) survey was carefully developed following an extensive literature review with a committee of staff within the field of I/DD with expertise in the areas of program implementation, policy development, and data management (Smith & Ashbaugh, 2001). It was initially developed and administered in 15 states in 1997 (National Core Indicators, 2017-2018b). In 2017-2018, 46 states participated in the study. Per NCI (2017-2018b), a key component of the study is gathering information directly from individuals with I/DD, regardless of their level of disability. Data collection for the NCI Study occurs in two sections. Section I is through face-to-face interviews with individuals with I/DD who receive supports and services. Section II can be completed by an individual with I/DD or a proxy chosen by that individual (National Core Indicators, 2017-2018a).

To avoid conflict, the NCI in-person survey cannot be administered by a paid support, relation, or close contact (National Core Indicators, 2017-2018b). Every state that participates in the annual survey is expected to complete a minimum of 400 surveys for the NCI study (National Core Indicators, 2017-2018a) to provide at least a 95% confidence level and +/- 5% margin of error. Participants are randomly sampled, must be eligible for I/DD supports and receive at least one publicly funded service in addition to case management (meaning that some level of staff support is being provided in their life), and must be 18 years old or older.

Smith & Ashbaugh (2001) detailed that reliability and validity were examined and established for the NCI Study. Inter-rater reliability was assessed on multiple occasions between 1997 and 2010, all resulting in 92%-93% agreement between raters. The National Association of State Directors of Developmental Disabilities Services (2012) shared that Cohen's Kappa scores ranged between 0.794 - 0.90, all above the conventional acceptable inter-rater reliability score of 0.70. Regarding validity, professionals within the field of I/DD initially developed the questions as a part of the survey, but individuals with I/DD were an integral part of ensuring pre-test validity. For individual interview validity, interviewers provide formal feedback following every interview to highlight any identified concerns with comprehension or consistency of answers to identify any potential validity concerns.

### **NCI Study: Ohio**

Since 2015, the Ohio State University Nisonger Center, in collaboration with DoDD, has collected data and overseen the administration of in-person surveys as a part of the NCI study throughout the state of Ohio (The Ohio State University: Nisonger Center, 2017). All 88 counties in Ohio are represented as a part of the random selection of individuals that are a part of the study. Staff through the Nisonger Center hire self-advocates (individuals with I/DD) and family members of individuals with I/DD to administer the surveys to individuals with whom they are not familiar. Participants are randomly selected based on the following criteria: I/DD eligibility determination through a county board of I/DD in the state of Ohio, the need and authorization of one type of service or staff support to meet a personal care need, and case management through the county board. Per A. Sharati, who assists with overseeing the data from the NCI study for

the Ohio DoDD, annually 1,500 individuals are initially sent the survey (personal communication, March 13, 2019). This occurs to ensure that well over 400 are returned and the data can be utilized as a part of the official NCI study data.

### ***2017-2018 Ohio NCI Study***

Data from the 2017-2018 NCI Study that was completed in the state of Ohio was used to quantitatively assess community engagement and friendship for individuals with I/DD as well as their residence, specifically whether they reside in a community home or institutional facility (National Core Indicators, 2017-2018).

### **Participants**

As noted, 1,500 participants (A. Sharati, personal communication, March 13, 2019) were recruited throughout the state of Ohio by the Nisonger Center (National Core Indicators, 2017-2018a). In total, over 90,000 individuals within the state of Ohio have I/DD and are eligible for county board supports (Ohio Association of County Boards, 2021). Participants were over the age of 18 and were found eligible for services and supports through a local county board of I/DD in the state. Some participants chose a proxy rather than completing the survey independently. Trained interviewers conducted face-to-face interviews with participants, and 766 participants completed the NCI study in Ohio in 2017-2018. There were not any legal, financial, or budgetary issues that impacted or informed the data collection or analysis.

### **Data Preparation**

I used the 2017-2018 Ohio NCI Study data set for this analysis (National Core Indicators, 2017-2018a). Staff from the Nisonger Center completed interviews with 766 individuals with developmental disabilities or a selected proxy (guardian, staff, advocate)

as a part of the Ohio NCI Study (The Ohio State University: Nisonger Center, 2019). Nisonger then handed the data set over to the Ohio DoDD, who then provided this data to me for further analysis. As this data was from an existing data set, upon receipt of the data from the Ohio DoDD, I conducted data cleaning for the purposes of this study.

Initially, Ohio DoDD provided me with a data set with information from 766 total respondents. The NCI Study includes a variable that assesses consistency of answers for both sections I and II of the data. I did not include 165 participants' responses in my data set due to inconsistent answers in section I and did not include one participant's responses in my data set due to inconsistent answers in both sections I and II. Therefore, 600 respondents were included as a part of my final data set. I also deleted multiple variables containing information outside of the scope of this research (i.e. transportation, insurance, healthcare, etc.).

### **Variable Creation**

After I uploaded the data into SPSS, I combined information from several existing variables to create a number of new variables. I did so because the way that the data was originally collected and organized did not allow for meaningful statistical analysis based on my study. I reorganized the existing information into more linear and appropriate variables as further explained below. I constructed new variables for race, living situation, and seeing one's friends.

### ***Race***

The NCI Study included eight individual variables for race. Specifically, it asked respondents to select "yes" or "no" to each of the following race categories: "American Indian or Alaskan Native", "Asian", "Black or African-American", "Pacific Islander",

“White”, “Latino”, “Other”, and “Don’t Know”. Participants could answer “yes” to only one or any combination of race questions to describe their racial identity. A total of 51 respondents did not reply to any of the racial identify questions. I created a singular variable that combined all race responses and included an option of “More Than One Race Selected.” In my newly created variable, I did not include the response of “Don’t Know” as no respondent had selected “yes” to that response. Table 1 (presented further along in this paper) presents detailed information on the newly created race variable. I coded my newly created race variable as follows: American Indian or Alaskan Native (0), Pacific Islander (1), Hispanic or Latino (2), White (3), Black or African American (4), Asian (5), More than one race selected (6).

### *Living Situation*

For the NCI Study, there were 15 selection options for the living situation variable: “ICF/IID, 4-6 residents with disabilities”; “ICF/IID, 7-15 residents with disabilities”; “ICF/IID, 16 or more residents with disabilities”; “Nursing facility”; “Other specialized institutional facility”; “Group living setting, 2-3 people with disabilities”; “Group living setting, 4-6 people with disabilities”; “Group living setting, 7-15 people with disabilities”; “Lives in own home or apartment”; “Foster care or host home (round-the-clock services provided in a single-family residence where 2 or more people with a disability live with a person or family who furnishes services – sometimes called shared living)”; “Foster care or host home (round-the-clock services provided in a single-family residence where only one person with a disability lives with a person or family who furnishes services – sometimes called shared living)”; “Parent/relative’s home”; “Homeless or Crisis Bed Placement”; “Other”; and “Don’t know” (National Core

Indicators, 2017-2018a). I created a new variable for “Type of home” in which I combined all institutional living options into one institutional facility response (all ICF/IID response options, nursing facility, and other specialized institutional facility) and all community group home living options into one community home response (all group living setting response options, lives in own home or apartment, and both foster care or host home). “Parent/relative’s home” and “Don’t know” remained as options for the new variable. I relabeled “Parent/relative’s home” to “Family home”. Both “Other” and “Homeless or Crisis Bed Placement” were not included in the new variable I created as no respondents selected those residential choices. I coded the newly created variable as follows: Community home (0), Institutional facility (1), Family home (2), Don’t know (3).

Due to a limited number of respondents residing within institutional settings, I made another adjustment to the “Type of home” category and created a second new variable. For this variable I combined institutional facility and community home into one response category, which I titled group home, to take a closer look at dependent variables for individuals residing within those homes versus individuals residing at home with family. For this independent variable, I discarded the Don’t know response option. I coded this variable as follows: Group home (0), Family home (1).

### **Descriptive Statistics**

Participants that responded “don’t know” or did not respond on one or more questions across the survey were still included within my dataset and relevant analyses to maximize the available data. Table 1 provides detailed demographic information about the respondents, including gender, race, and residential location information.



**Table 1***Respondents' Demographic Information*

|          | Variable                          | Frequency (N) | Percentage (%) |
|----------|-----------------------------------|---------------|----------------|
| Gender   | Male                              | 332           | 55.3           |
|          | Female                            | 230           | 38.3           |
|          | No response                       | 38            | 6.3            |
| Race     | American Indian or Alaskan Native | 1             | 0.2            |
|          | Hispanic or Latino                | 8             | 1.3            |
|          | White                             | 421           | 70.2           |
|          | Black or African American         | 103           | 17.2           |
|          | Asian                             | 1             | 0.2            |
|          | Other                             | 7             | 1.2            |
|          | More than one race selected       | 8             | 1.3            |
|          | No Response                       | 51            | 8.5            |
| Location | Rural                             | 10            | 1.7            |
|          | Small Town                        | 35            | 5.8            |
|          | Metropolitan                      | 408           | 68.0           |
|          | Micropolitan                      | 88            | 14.7           |
|          | No response                       | 59            | 9.8            |

Participants were primarily male (55.3%), identified as white (70.2%) and most typically resided in a metropolitan area (68.0%). Table 2 provides further information about participants' level of guardianship and the level of I/DD, if applicable.

**Table 2***Descriptive Variables Specific to Individuals with I/DD*

| Variable                            | Frequency (N) | Percentage (%) |
|-------------------------------------|---------------|----------------|
| <b>Legal Guardianship Status</b>    |               |                |
| No Guardian                         | 359           | 59.8           |
| Limited Guardianship                | 61            | 10.2           |
| No distinction between limited/full | 13            | 2.2            |
| Full Guardianship                   | 124           | 20.7           |
| Don't Know                          | 2             | 0.3            |
| No Response                         | 41            | 6.8            |
| <b>Level of I/DD</b>                |               |                |
| No I/DD Diagnosis                   | 64            | 10.7           |
| Mild                                | 284           | 47.3           |
| Moderate                            | 158           | 26.3           |
| Severe                              | 16            | 2.7            |
| Profound                            | 2             | 0.3            |
| Unspecified                         | 20            | 3.3            |
| I/DD Diagnosis Unknown              | 9             | 1.5            |
| No response                         | 47            | 7.8            |

Most respondents did not have a legal guardian (59.8%) and were mostly within the mild to moderate range of I/DD or did not have an I/DD diagnosis (84.3%). That percentage is a stark difference in comparison to the number of respondents within the severe to profound range of I/DD (3.0%).

The literature review for this research centered around institutional and community homes for individuals with I/DD. However, the NCI Study provided an additional housing variable, as noted in Table 3, family home. A family home for the purposes of the NCI Study is any respondent that answered that they resided in a home

with a family member. As the intricacies of life within a family home and environment are different than those within a home in either the community or an institution, a third level of the type of home variable (in addition to community home or institutional home) was created to include individuals residing within a family home. However, due to only 23 total individuals residing within institutional facilities, a number much lower than expected comparisons between the group of individuals residing in an institutional home and the group of individuals residing in a community home became problematic due to unequal sample sizes. Therefore, to honor statistical assumptions around sample sizes and maximize the opportunity to learn the most about the role type of home plays on community engagement and friendship, additional analyses were conducted by collapsing the type of home variable into two levels – individuals residing in family homes versus those residing in group homes (institutional or community homes).

**Table 3**

*Living Situation*

| Variable           | Frequency ( <i>N</i> ) | Percentage (%) |
|--------------------|------------------------|----------------|
| Type of Home       |                        |                |
| Community Home     | 281                    | 50.4           |
| Institutional Home | 23                     | 4.1            |
| Family Home        | 251                    | 45.0           |
| Don't Know         | 3                      | 0.5            |

**Present Study Variables**

Specific NCI questions and answers for the Ohio 2017-2018 survey were provided to me from A. Sharati with DoDD following the defense of the proposal for the DIP, Creighton University Social/Behavioral Institutional Review Board (Creighton IRB) approval (Appendix A), and then IRB approval through the State of Ohio (Appendix B).

Therefore, detailed information about the survey questions, specifically how questions were asked to garner information (including how each was measured), were not available prior to the development of this study. However, some areas of questioning and general information about the type of data gathered were available to me from the Adult In-Person Survey: Ohio 2017-2018 Report (National Core Indicators, 2017-2018a). This report provided me with an overview of the questions asked, although many questions in the report were simplified and not the full questions that were asked of survey respondents. The variables I analyzed in this research are discussed below.

### **Independent Variable**

The independent variable in this quantitative study is the type of home in which the individual with I/DD resides, an institutional setting, home in the community, or family home within the state of Ohio. A second wave of deinstitutionalization is occurring throughout the state of Ohio (Horvath & Kleiman, 2015) and deinstitutionalization outcomes are often centered around increased community engagement and friendship for those in community homes (Chowdhury & Benson, 2011; Larson et al., 2012b). Therefore, assessing differences regarding community engagement and friendship based on type of residence is timely.

For this study, community home versus institutional home was the initial focus, but due to a small number of respondents residing within institutional settings, analyses were also conducted comparing community engagement and friendship for those residing in institutional or community homes (referred to as group homes) versus those residing in a family home. I provided detailed information regarding the creation of the type of home variable under the Living Situation heading above as well as in Table 3.

## **Dependent Variables**

I assessed two constructs, community engagement and friendship, as a part of this study. Each construct was measured by two distinct dependent variables, resulting in a total of four dependent variables.

### ***Community Engagement Variables***

The two community engagement dependent variables focused on respondents going into their community and engaging in choice activities as well as participating as a member of community groups. Each variable was measured by a singular question on the NCI Study (National Core Indicators, 2017-2018a).

The first community engagement question was as follows: “Are you able to go out and do the things you like to do in the community as often as you want?” (p. 43). The response options for this question were: “No, I do go out and do things that I like, but I’d like to do more” ( $N = 111$ ), “Yes, I do the things I like to do as much as I like to” ( $N = 405$ ), “Not applicable – doesn’t name things s/he likes to do” ( $N = 19$ ), or “Don’t know, no response, unclear response” ( $N = 37$ ). For my analyses, I discarded the not applicable and don’t know responses and analyzed “No, I do go out and do things that I like, but I’d like to do more” (coded 0) and “Yes, I do the things I like to do as much as I like to” (coded 1), based on residence.

The second community engagement question was as follows: “Do you participate as a member of community groups in your community?” (p. 42). The response options for this question were: “No” ( $N = 349$ ), “Yes” ( $N = 211$ ), or “Don’t know, no response, unclear response” ( $N = 8$ ). For my analyses, I discarded the don’t know responses and analyzed “No” (coded 0) and “Yes” (coded 1), based on residence.

### *Friendship Variables*

The two friendship dependent variables focused on respondents seeing friends as often as they liked and having a best friend, or someone they were close with, in their life. Each variable was measured by a singular question on the NCI Study (National Core Indicators, 2017-2018a).

The first friendship question was as follows: “Can you see your friends when you want to?” (p. 32). The response options for this question were “No, cannot always see friends” ( $N = 36$ ), “Yes” ( $N = 420$ ), “Sometimes can’t see friends” ( $N = 55$ ), “Not applicable” ( $N = 38$ ), or “Don’t know, unclear response, no response” ( $N = 22$ ). I did not include not applicable and don’t know responses in my analyses. I left the answer “Yes” untouched and combined the answers “Sometimes can’t see friends” and “No, often can’t see friends” into a category of “No, cannot always see friends” ( $N = 91$ ). I then analyzed “No, cannot always see friends” (coded 0) and “Yes” (coded 1), based on residence.

The second friendship question was as follows: “Do you have a best friend, or someone you are really close to? (Is there someone you can talk to about personal things?)” (p. 32). The response options for this question were “No, does not have a best friend” ( $N = 116$ ), “Yes, has a best friend” ( $N = 414$ ) or “Don’t know, no response, unclear response” ( $N = 36$ ). For my analyses, I did not include the don’t know response, and analyzed “No, does not have a best friend” (coded 0) versus “Yes, has a best friend” (coded 1), based on residence.

### **Additional Variables of Interest**

Two additional variables, gender and level of I/DD, were gathered as a part of the NCI Study. I analyzed these variables to determine their influence on seeing one's friends based on type of residence.

#### ***Gender***

As a part of the Ohio National Core Indicators (2017-2018a) Survey, gender was measured as a trivariate construct, offering male, female, or other as selections. However, 0% of respondents selected other as an option. Therefore, for my analyses, I used this in bivariate form, males (scored 0) and females (scored 1).

#### ***Level of I/DD***

The Ohio In-Person National Core Indicators (2017-2018a) Survey asked if an individual had a diagnosis of an intellectual disability, and for those that answered yes, the disability was then ranked as mild, moderate, severe, profound, or marked as unspecified. I scored this variable as follows: no I/DD diagnoses (0), mild I/DD (1), moderate I/DD (2), severe I/DD (3), profound I/DD (4), unspecified level of I/DD (5), I/DD diagnosis unknown (6).

### **Ethical Considerations**

Individuals with I/DD are a vulnerable and protected group of citizens. Therefore, the fact that prior collected data is being utilized limited any additional risk to individuals with I/DD. However, it should be noted that the research was still regarding individuals with I/DD, so recommendations from the findings of this study were provided with careful consideration of any repercussions that they could have on individuals with I/DD. As stated within the literature review, there are multiple considerations that can be

made when assessing quality of life, community engagement, and friendship for individuals with I/DD.

All data that was provided through the Ohio DoDD and analyzed was maintained on a password protected computer and within a password protected file. The data provided had identifiers removed so that no individual person level data could be utilized to trace back to any specific research participant or individual with I/DD. At the completion of the study analysis, all data was deleted.

### **Permissions for the Study**

As the Housing Coordinator for Cuyahoga DD, permissions were provided both from the Community and Medicaid Services Department of Cuyahoga DD (J. Barath, January 29, 2018), the direct department in which I work, as well as the Human Resources Department of Cuyahoga DD (N. Tsevdos, personal communication, February 2, 2018). Permission was granted if direct surveys were not conducted by the researcher with individuals residing within the county of Cuyahoga.

I received approval from the Creighton University IRB on October 21, 2020 (Appendix A). Additionally, I received approval from the Ohio Department of Health Human Subjects IRB on December 1, 2020 (Appendix B).

Following written permission to access 2017-2018 Ohio NCI Study data (My Ohio, 2020), the Ohio DoDD released data from the 2017-2018 Ohio NCI Study data upon approval of my study proposal by the state of Ohio Institutional Review Board. The data provided did not provide the county of residence of the survey participant, due to concern that with that information, specific individuals within Cuyahoga County could be



identified due to my work for Cuyahoga DD. Instead, residence was coded by county size (micropolitan, metropolitan, rural, and small town).

### **Summary**

In summary, data collected from the NCI Study conducted in the state of Ohio in 2017-2018 (National Core Indicators, 2017-2018) was utilized as a part of this study. Analyses through SPSS were completed to determine community engagement and friendship for individuals with I/DD based on institutional or community residence in the state of Ohio. The results can better inform leaders within the field of I/DD in the state of Ohio to provide the best possible options for individuals with I/DD to better improve community engagement and friendship outcomes as desired by individuals with I/DD.

## CHAPTER FOUR: RESULTS AND FINDINGS

In the following chapter, I explored my research question: How do ratings of community engagement and friendship vary based on residential location (community home versus institution) for individuals with I/DD within the state of Ohio? Due to a small respondent sample who resided in institutional homes, which limited findings, I expanded my research to analyze ratings of community engagement and friendship based on institutional and community home (group home) versus family home residence. Finally, I discuss my findings in relation to the research question.

### **Data Analysis**

I utilized SPSS for all quantitative data analyses. I primarily used Chi-Square tests to identify whether there was a significant difference in community engagement and friendship based on residence, community home versus institution or family home versus group home. Additionally, I used Fisher's Exact test when the sample size did not meet the required standard set for a Chi-Square analysis.

I used the Kruskal-Wallis rank-sum test to explore additional variables of interest, including gender and level of I/DD, regarding seeing one's friends. These analyses provided additional information to determine if there was a need to focus on gender or level of I/DD when examining ways to increase friendship for individuals with I/DD.

### **Results and Findings**

This study's purpose and related analyses were specifically focused on community engagement and friendship due to the close alignment of those constructs to overall quality of life for individuals with I/DD (Friedman & Rizzolo, 2018; Salkever, 2000). However, regarding quality of life, under the survey area of satisfaction, the NCI

Study (National Core Indicators, 2017-2018a) asked if services and supports help the person “live a good life” (p. 55). The response options for this question were “No” ( $N = 8$ ), “Yes” ( $N = 515$ ), “In between” ( $N = 32$ ), or “Don’t know, no response, unclear response” ( $N = 16$ ). It is notable that for the 2017-2018 Ohio NCI Study, 85.8% of individuals and/or guardians responded that they felt, yes, services and supports helped them live a good life (Table 4). Only eight (1.3%) respondents stated no, services and supports did not help them live a good life. Overall, a significant portion of individuals with I/DD or their chosen proxy responded positively to this question.

**Table 4**

*Services and Supports Help the Respondent Live a Good Life*

| Response                                  | Frequency | Percentage (%) |
|---|-----------|----------------|
| Yes                                       | 515       | 85.8           |
| No  | 8         | 1.3            |
| In between                                | 32        | 5.3            |
| Don’t know, no response, unclear response | 16        | 2.8            |
| Missing                                   | 29        | 4.8            |

Throughout the rest of this chapter, I will focus on the constructs of community engagement and friendship and review results from analyses comparing dependent variables based on type of residence.

### **Community Engagement**

The construct of community engagement was measured by two separate questions on the NCI Study. For the first question, respondents were asked if they were able to go out and do the things they like to do as much as they’d like. For individuals unable to express activities of choice in their day-to-day life, the question was marked as not applicable. Otherwise, the respondent was able to answer from two distinct options: “yes,

I do the things I like to do as much as I like,” or “no, I do go out and do some things I like but I’d like to do more.” If the respondent did not choose from those options, “don’t know, no response, or unclear response” was selected. I analyzed the difference in the number of individuals who responded yes versus the number who responded no.

The second community engagement question asked respondents if they participated as a member of community groups in their community. The response options were “yes,” “no,” or “don’t know, no response, or unclear response. I analyzed the difference in the number of individuals who stated yes versus the number who stated no.

I analyzed survey questions within the constructs of community engagement utilizing the Chi-Square Test when the necessary requirements were met. To utilize Chi-Square as the assessment, every cell must have a frequency count of five or greater (UCLA: Statistical Consulting Group, n.d.). This requirement was met for all variables within the construct of community engagement.

### ***Institutional Home versus Home in the Community***

The analysis included respondents who reported residing in an institutional home ( $N = 23$ ) versus a home in the community ( $N = 281$ ). A series of Chi-Square analyses found that there were not any significant differences in community engagement based on residence. Specifically, the number of individuals that were able to go out and do the things they wanted as much as they liked did not differ by residence,  $\chi^2(1, N = 274) = 2.72, p = .10$ .

In regard to participation in community groups, the number of individuals that participated in groups in the community did not significantly differ by residence,  $\chi^2(1, N = 300) = 0.21, p = .64$ . Therefore, the data did not reveal a meaningful difference in the

number of respondents who could go out and do things they liked as much as they liked or participated in groups in the community based on residence. The details of these analyses are displayed in Table 5.

**Table 5**

*Community Engagement: Institutional Home versus Community Home*

| Response                                | Institutional Home |          | Community Home |          |
|---|--------------------|----------|----------------|----------|
|   | <i>N</i>           | (%)      | <i>N</i>       | (%)      |
| <b>Can Go Out as Much as One Likes</b>  |                    |          |                |          |
| Yes                                     | 10                 | (62.50%) | 206            | (79.84%) |
| No                                      | 6                  | (37.50%) | 52             | (20.16%) |
| <b>Participates in Community Groups</b> |                    |          |                |          |
| Yes                                     | 9                  | (40.91%) | 100            | (35.97%) |
| No                                      | 13                 | (59.09%) | 178            | (64.03%) |

***Family Home versus Group Home***

The analysis included respondents who reported residing in a family home ( $N = 251$ ) versus a community or institutional home ( $N = 304$ ). For simplicity's sake, I will refer to those residing within a community or institutional home as a group home. I chose to conduct this analysis because those residing in a family home function differently than those residing in a group home, so made the reasonable assumption that friendship and community engagement may differ. For this analysis, there were not any significant differences identified based on residence. Specifically, the number of individuals that were able to go out and do the things they wanted as much as they liked did not differ by residence,  $\chi^2(1, N = 498) = 0.04, p = .85$ . Additionally, the number of individuals that participated in groups in the community did not differ by residence,  $\chi^2(1, N = 543) = 0.91, p = .34$ . Details of these findings are displayed in Table 6. While the analyses did

not reveal a statistically significant difference based on residence, it is notable that most respondents, regardless of residence, did not participate in groups in the community (59.67-63.67%). This finding is further discussed in Chapter 5.

**Table 6**

*Community Engagement: Family Home versus Group Home*

| Response                                | Family Home |          | Group Home |          |
|---|-------------|----------|------------|----------|
|   | <i>N</i>    | (%)      | <i>N</i>   | (%)      |
| <b>Can Go Out as Much as One Likes</b>  |             |          |            |          |
| Yes                                     | 175         | (78.13%) | 216        | (78.83%) |
| No                                      | 49          | (21.87%) | 58         | (21.17%) |
| <b>Participates in Community Groups</b> |             |          |            |          |
| Yes                                     | 98          | (40.33%) | 109        | (31.33%) |
| No                                      | 145         | (59.67%) | 191        | (63.67%) |

### **Friendship**

The second construct, friendship, was measured by two separate questions on the NCI Study. The first friendship question asked respondents if they had a best friend. Respondents were able to answer yes, no, or don't know, and I analyzed the difference in the number of individuals who stated yes versus the number who stated no. The second friendship question asked respondents if they could see friends as often as they like. I analyzed this variable by comparing individuals who stated yes versus those who stated no, not always able to see friends.

I analyzed survey questions within the construct of friendship utilizing the Chi-Square Test when the necessary requirements were met. However, due to the low number of respondents residing within institutional homes, the assumption of a frequency of five

within every cell was not always met within the friendship construct (UCLS: Statistical Consulting Group, n.d.), so I then used Fisher's Exact Test for analysis.

### *Institutional Home versus Home in the Community*

As noted, to analyze differences regarding friendship based on residence, I ran a series of Chi-Square and Fisher's Exact tests for respondents who reported residing in an institutional home ( $N = 23$ ) versus a home in the community ( $N = 281$ ). I did not include any individuals who resided in a family home ( $N = 251$ ). A series of Chi-Square and Fisher's Exact analyses did not reveal any significant difference in friendship based on residence. Specifically, I ran a Chi-Square test, since the frequency assumption of five within every cell was met, to determine that the number of individuals that had a best friend did not differ by residence,  $\chi^2(1, N = 280) = 1.13, p = .29$ , as shown in Table 7.

The assumption of  $N = 5$  within every response category was not met when considering the question of whether respondents were able to see their friends as often as they desired. Therefore, I was not able to use a Chi-Square test for this analysis, and instead ran a Fisher's Exact test (UCLA: Statistical Consulting Group, n.d.). The number of individuals that were able to see their friends as often as they desired did not differ based on residence, Fisher's Exact ( $N = 270$ ),  $p = .75$  (2-tailed), also shown in Table 7.

For both dependent variables that were utilized to take a closer look at the construct of friendship, having a best friend and being able to see one's friends, there was not a statistically significant difference for individuals residing in an institutional home versus a home in the community. Nonetheless, due to the small respondent size for individuals with I/DD residing in institutional homes ( $N = 23$ ), assumptions based on the findings should be made with caution.

**Table 7***Friendship: Institutional Home versus Community Home*

| Response                     | Institutional Home |          | Community Home |          |
|------------------------------|--------------------|----------|----------------|----------|
|                              | <i>N</i>           | (%)      | <i>N</i>       | (%)      |
| Best Friend                  |                    |          |                |          |
| Yes                          | 14                 | (70.00%) | 208            | (80.00%) |
| No                           | 6                  | (30.00%) | 52             | (20.00%) |
| Can See Friends              |                    |          |                |          |
| Yes                          | 18                 | (90.00%) | 211            | (84.40%) |
| No, can't always see friends | 2                  | (10.00%) | 39             | (15.6%)  |

*Family Home versus Group Home*

Due to the small sample size of individuals with I/DD residing in institutional homes, I further analyzed the sub-area of individuals residing in a family home ( $N = 251$ ) versus a group home ( $N = 304$ ). I ran a series of Chi-Square analyses, which did not reveal any statistically significant differences based on residence. The number of individuals that had a best friend did not differ by residence,  $\chi^2(1, N = 513) = 1.01, p = .31$ . See Table 8 for details.

Additionally, the number of individuals that were able to see their friends as often as they desired based on residence did not reveal a statistically significant difference,  $\chi^2(1, N = 493) = 2.89, p = .09$ . However, while this analysis did not reach the level of traditionally accepted statistical significance ( $p < .05$ ), it is approaching significance. To elaborate, this  $p$ -value suggest that there is about a 1 in 10 chance of being wrong that there is a relationship between these variables. Similarly, the Chi-Square value (2.89) represents a higher degree of difference between the two groups of individuals, even if that is not statistically significant. Therefore, this area deserves further analysis. The



frequency of seeing versus not seeing friends based on residence better highlights the difference between groups (see Table 8). While only 15.19% of individuals residing in a group home responded that they were not able to see friends as often as they desired, 21.08% of individuals residing with family responded that they were also not able to see friends. Simply comparing this data across percentages, a greater percentage of individuals residing in a group home (84.81%) reported seeing friends more often than those in a family home (78.92%). As this analysis approached statistical significance, I ran additional analyses to more closely look at whether there were any gender differences and differences based on level of developmental disability.

**Table 8**

*Friendship: Family Home versus Group Home*

| Response                     | Family Home |          | Group Home |          |
|------------------------------|-------------|----------|------------|----------|
|                              | <i>N</i>    | (%)      | <i>N</i>   | (%)      |
| <b>Best Friend</b>           |             |          |            |          |
| Yes                          | 176         | (75.54%) | 222        | (79.29%) |
| No                           | 57          | (24.46%) | 58         | (20.71%) |
| <b>Can See Friends</b>       |             |          |            |          |
| Yes                          | 176         | (78.92%) | 229        | (84.81%) |
| No, can't always see friends | 47          | (21.08%) | 41         | (15.19%) |

***Seeing One's Friends: Additional Analyses***

I used the Kruskal-Wallis test for these analyses. While a one-way ANOVA is a more commonly recognized analyses, the assumptions for a one-way ANOVA were not met by this data set. Specifically, a one-way ANOVA requires categorical independent variables and a normally distributed interval dependent variable (UCLA: Statistical Consulting Group, n.d.). The Kruskal-Wallis test was used instead of a one-way ANOVA

due to the nature of the categorical independent and dependent variables. Further, due to the small sample size for the group of individuals that responded they resided in an institutional facility, all additional analyses compared individuals residing in a group home versus a family home.

The Kruskal-Wallis analyses did not reveal any significant difference in ratings for seeing one's friends, when comparing type of residence, for males or females. Specifically, for respondents who identified as females, there was not a significant difference in seeing one's friends, when comparing family home versus group home,  $\chi^2(1, N = 122) = 0.87, p = .35$ . Similarly, for males, there was not a significant difference in seeing one's friends, when comparing family home versus group home,  $\chi^2(1, N = 147) = 2.53, p = .11$ .

I also ran Kruskal-Wallis analyses to determine whether there was a significant difference on seeing one's friends depending on type of residence (family home versus group home) for each reported level of I/DD (Table 9). In other words, I compared those residing in a family home versus those residing in a group home to determine differences in seeing one's friends separately for each level of I/DD. I did not run analyses on individuals who did not have a diagnosis of I/DD. I found no statistically significant differences with seeing friends for any level of I/DD ( $p$  ranged from .50 - .78). Therefore, there was not a statistically significant difference in seeing one's friends for all levels of I/DD. Please note that Kruskal-Wallis analyses are reported with Chi-Square values..

**Table 9***Seeing One's Friends and Level of I/DD*

| Level of I/DD       | Can See One's Friends |     | Chi-Square | <i>p</i> -value | <i>df</i> |
|---------------------|-----------------------|-----|------------|-----------------|-----------|
|                     | No                    | Yes |            |                 |           |
| Mild ID             | 48                    | 205 | 0.08       | .78             | 1         |
| Moderate ID         | 20                    | 120 | 0.21       | .65             | 1         |
| Severe I/DD         | 2                     | 10  | 0.40       | .53             | 1         |
| Profound I/DD       | 0                     | 2   | 0.40       | .53             | 1         |
| Unspecified/Unknown | 1                     | 27  | 0.45       | .50             | 1         |

### Discussion

Overall, there were no significant statistical differences identified for either community engagement or friendship based on residence. This was the case when comparing institutional homes versus community homes and when comparing family homes versus group homes. Therefore, when considering an institutional versus community home, residing in the community does not necessarily increase ratings of community engagement or friendship. Additionally, the same could be said for residing in the community versus a family home.

These findings parallel Lucas-Carrasco and Salvador-Carullo's (2012) study on overall life satisfaction based on residence in Catalonia, Spain where the researchers determined that residence alone did not solely affect life satisfaction. Although emphasis in Ohio has been placed on the importance of deinstitutionalization to improve community engagement and friendship opportunities, it appears that for improvements to be made within those areas, more factors come into play than residence alone.

### **Community Engagement**

Regarding community engagement, Heller et al. (1998) found that individuals in community homes versus institutional homes had statistically significant higher levels of community engagement. The results from my study do not show that difference but could be limited due to the sample size of individuals residing in institutional homes as well as the limited number of survey questions that assessed the construct. Apart from the lack of significant difference for community engagement ratings based on residence for this study, it is of note that 20.16% of individuals residing in a community home and 37.5% of individuals residing in an institutional home responded they were not able to go out and do what they desired as often as they pleased. Additionally, 59.67% of individuals residing in a family home and 63.67% of individuals residing in a group home did not participate in community groups as often as they wanted. Verdonschot et al. (2009) emphasized the lack of community inclusion and engagement for individuals with I/DD, and the results from this study showcase that continuing concern.

### **Friendship**

Although there were not any statistically significant differences in friendship based on residence, 15.19% of individuals residing in a group home and 21.08% of individuals residing in a family home noted that they were not able to see their friends as often as they desired. Those ratings are concerning based on Friedman and Rizzolo's (2018) findings that improved friendship connections increased almost every outcome area and overall satisfaction within one's life based on a study they conducted with just under 1,300 individuals with I/DD.

### **Research Limitations**

There are two key limitations that should be taken into consideration when considering the findings from this research. The first: the data was provided using an existing instrument and an archived data set, the 2017-2018 Ohio NCI Study. Therefore, questions were not able to be tailored to specifically and directly assess individuals with I/DD' feelings of satisfaction. Rather, questions from the NCI study that most closely aligned with the purpose of my study were selected and analyzed. The second key limitation to working with an existing data set: the respondent sample size for those residing in institutional settings was much smaller ( $N = 23$ ) than anticipated. If I had been able to survey these groups, I would have endeavored to recruit a larger pool of respondents who were residing in institutional facilities. The small sample size limited both the analyses that I was able to conduct as well as the interpretations that I was then able to make from the findings.

### **Summary**

This chapter presented results and findings regarding community engagement and friendship for individuals with I/DD in the state of Ohio based on residence. I conducted analyses comparing individuals residing in an institutional home versus a community home and then, due to the limited sample size of individuals residing within institutional homes, comparing individuals residing in a group home versus a family home. Additional analyses assessed whether gender or level of I/DD were an influencing variable when considering the variable of seeing one's friends. Although there were no statistically significant differences identified through any analyses, seeing one's friends as often as one liked based on residing in a family versus group home approached a level of

statistical significance ( $p = .09$ ). In the next chapter, I will provide recommendations on how community engagement and friendship can be increased for individuals with I/DD, regardless of residence.

## CHAPTER FIVE: PROPOSED SOLUTION AND IMPLICATIONS

Since analyses for this study showcased that there was no overall significant difference in community engagement or friendship for individuals with I/DD residing in Ohio based on residence, my solutions focus on improving community engagement and friendship outcomes regardless of residential location. I share my initial aim statement, propose solutions, detail implementation procedures for the solutions, and discuss practical, research-based, leadership-centric implications.

### **Aim Statement**

The aim of this study was to use findings from this study, as well as previous research, to develop recommendations for leaders in the I/DD field in Ohio to increase community engagement and friendship for individuals with I/DD, based on residence.

### **Overview of Findings**

#### **Community Engagement**

There were no statistically significant differences in community engagement based on residence, institutional home versus community home or family home versus group home. However, that does not mean people with developmental disabilities have achieved desired levels of community engagement. Instead, the findings simply mean that there is a similar level of community engagement, independent of residence.

#### ***Community Engagement: Can Go Out as Much as One Likes***

Overall, 20%-37.5% of respondents stated that they were not able to go out as much as they liked (refer to Tables 5 and 6), regardless of residence. In other words, over one out of five respondents were not satisfied with the amount that they were able to go out and do the things they desired.

***Community Engagement: Participates in Community Groups***

Even if individuals participate in groups in the community, it does not necessarily mean that they are or feel included – the previously noted difference of community engagement versus community inclusion. Nonetheless, only 31%-41% of respondents stated that they participated in groups in their community (refer to Tables 5 and 6). While it cannot be assumed that respondents were dissatisfied with their level of community group participation (perhaps they did not want to participate in community groups), it is notable that such a large percentage of individuals did not participate in any community groups. This lack of community group participation is represented within solutions that I present to this real-world problem.

**Friendship**

Overall, there were no statistically significant differences in friendship based on residence, institutional versus community or family home versus group home. However, that does not mean that there are not concerns regarding friendship for respondents as a part of this study. Rather, it just means that there are similar friendship ratings, independent of residence.

***Friendship: Best Friend***

Between 70%-80% of respondents stated that they had a best friend (refer to Tables 7 and 8). However, as noted previously, the full question for this variable was as follows: “Do you have a best friend, or someone you are really close to? (Is there someone you can talk to about personal things?)” (National Core Indicators, 2017-2018a, p. 32). Therefore, 20-30% of respondents felt they did not have anyone with whom they were really close or could talk to about personal things. Bigby, et al. (2017) conducted



focus groups and individual interviews with a total of 24 individuals with I/DD residing in community supported living homes in Victoria, Canada. Even residing in homes in the community, the researchers identified that most individuals experienced loneliness and struggled to form friendships. This further emphasizes concerns regarding friendship, no matter where someone with I/DD might reside.

### ***Friendship: Can See Friends***

Although no statistically significant differences in friendship based on residence were identified, analyses comparing individuals residing in a family home versus a group home did approach a level of statistical significance ( $p = .09$ ). Overall, 10%-21% of respondents answered that they were not always able to see their friends (refer to Tables 7 and 8). Responses about not seeing one's friends as often as one liked was highest for those residing within a family home (21.08%). Therefore, to increase ratings regarding seeing one's friends, one part of the solution, detailed below, focuses on the need to identify why there is a higher percentage of individuals residing within family homes that are not able to see friends as often as they desire.

### **Proposed Solutions**

Haslam et al. (2011) focused on the importance of leaders being in-group champions by identifying as a part of a group they are seeking to lead. To be an effective leader, it is critical to fully understand what is desired by those for whom a leader is seeking change. That leadership principle holds true for the concern at hand. Individuals with I/DD need to be a central part of the solution to achieve results that will make a positive difference in terms of community engagement and friendship.

I present a multi-faceted solution based on previously conducted research as well as findings from my study. Overall, my proposed solutions focus on the need to gather more information to reach the best possible solutions to increase community engagement and friendship for individuals with I/DD.

### **Survey Recommendations**

My initial research interest was to study satisfaction regarding community engagement and inclusion as well as friendship. As I utilized data from an already completed study that did not directly assess ratings of satisfaction, I was not able to conduct my initial research plan. However, in light of the second wave of deinstitutionalization in the state of Ohio, I recommend a study specifically centered around satisfaction. While the NCI Study measures several constructs, it does not directly address deinstitutionalization or differences in satisfaction based on residence. Based on previous research, such as Chowdhury and Benson (2011) who identified that deinstitutionalization does not always result in increased levels of satisfaction, and the findings of my study, I recommend a research study based on levels of satisfaction regarding community engagement and inclusion, friendship, and quality of life, based on residence. Additionally, it would be beneficial for such a survey to consider the amount of time someone resided within their residence, to determine if areas of satisfaction remained the same, increased, or even decreased following a change in type of residence.

### **Seeing One's Friends While Residing in a Family Home**

Although there were not any statistically significant findings from the data analyses in the traditional sense, the friendship variable of seeing one's friends based on residence, family home versus group home, neared a level of statistical significance ( $p =$

.09). Respondents residing within a family home were only able to see their friends as often as they liked 79% of the time (Table 8) compared to respondents residing within a group home who were able to see their friends as often as they liked 85% of the time. This is a concern based on research that suggests friendship is directly correlated with increased quality of life (Salvador-Carulla, 2012). Therefore, I propose gathering additional information from individuals with I/DD residing with family members regarding seeing friends. This information should include what the respondents specifically desire seeing their friends, barriers to seeing friends, along with additional specific details regarding how often they would like to see friends, how often they are able to see friends, and friendship satisfaction ratings. Additionally, information should be gathered from respondents' family members regarding barriers to supporting their loved one with I/DD to see friends along with recommendations that would support them to increase their loved one to see friends. This information would be able to be gathered through a survey sent out to individuals and family members through an identified county board of I/DD.

Information gathered from individuals with I/DD and family members can then be utilized by the identified county board to assist families to overcome identified barriers to improve the frequency at which individuals with I/DD see their friends. Bigby (2008) highlighted concerns in terms of individuals with I/DD building and maintaining friendships. My proposal would help gather information that could determine specific concerns related to building and maintaining friendships, so those barriers could be overcome by others. More information is needed in this area before larger solutions can be fully identified.

## **Community Engagement**

To increase community engagement, I propose action research to gather additional information regarding community engagement, inclusion, and friendship for individuals with I/DD. Friedman and Rizzolo (2018) spoke of the potential cyclical effect of community engagement and increased friendship. It would be beneficial to determine if that potential was a reality. Initially, I propose identifying a group of 12 individuals with I/DD from a local county in Ohio and connected to that county board of I/DD. While a group of 12 will not increase community engagement for individuals with I/DD overall, it will further inform how to best move forward to improve community engagement outcomes for individuals with I/DD. These individuals should be selected from a combination of institutional, family, and community homes.

Each individual will have the opportunity to identify a specific community group they are interested in joining. To ensure that this study meets the desired outcome for each specific individual with I/DD, it is important for there to be a wide range of community groups. As determined through my research, most respondents to the NCI Study (National Core Indicators, 2017-2018a) did not participate in any community group (see Tables 5 and 6). Therefore, certain parameters will be set around community groups, such as requiring that there be at least three other community members that are a part of the group, and that the group meet on at least a monthly basis, but otherwise, each participant will be able to select a group in which they are motivated to participate (anything from a workout group, a coffee club, a reading group, an art or music class, religious service, or something else desirable by the study participant).

With the support of their individual team (county board staff, provider staff, family members, etc.), each study participant will have the opportunity to engage with their chosen group over the course of one year. Upon identification of the community group, I will focus on preparing community members that are a part of community groups to actively engage with the study participants, especially given the community apprehension and hesitation to engage with individuals with I/DD that researchers have identified (McLean et al., 2017; Van Alphen et al., 2010). Throughout the year of active community engagement, I will collect information on the following:

- Barriers to participation,
- Continued interest in participating in the group,
- Satisfaction regarding community engagement,
- Feelings of inclusion or lack of inclusion regarding group participation,
- Community connections developed from the group, and
- Friendships developed from the group.

Amado et al. (2013) specifically emphasized a lack within the research and literature regarding how community participation can lead to friendships and additional community engagement opportunities. Therefore, I plan to gather information in that area as a part of this pilot project. The information gleaned from this initial community engagement endeavor can then be utilized to grow community engagement opportunities for individuals with I/DD on a larger scale. Initially, I propose a small group to work through any barriers to full participation and ensure that the initiative is successfully able to increase community inclusion and satisfaction from the perspective of the individuals

with I/DD that partake in the initiative.

### **Evidence that Supports the Proposed Solutions**

Johnson (2015) emphasized the moral imperative of leaders to work toward inclusion for those who are not fully accepted or included into groups. The findings from this research study provide an opportunity to work toward community participation and inclusion for individuals with I/DD. However, to be a transformational leader (Northouse, 2013), it is critical for leaders working toward a community inclusion solution by working *with* individuals with I/DD, rather than simply *for* such individuals.

Transformational leadership necessitates collaboration between leaders and individuals for whom those leaders are attempting to exact positive change. Therefore, my proposed solutions focus on gathering information directly from individuals with I/DD in order to make informed and collaborative leadership decisions and ensuring collaborative efforts toward greater community inclusion as desired by each specific individual.

### ***Need for Additional Research***

Researchers have made recommendations regarding gathering additional information directly from individuals with I/DD related to deinstitutionalization (Cushing, 2015; Jones & Gallus, 2016). Additionally, the lack of research regarding the constructs of community engagement and friendship based on residence, especially given the 2<sup>nd</sup> wave of deinstitutionalization in Ohio, presents an opportunity to gather information that can increase knowledge and allow for more targeted recommendations for leaders to identify solutions to increase satisfaction in these areas.

### ***Collaborative Efforts toward Community Inclusion***

Cushing (2015) noted that increasing community for individuals with I/DD is often a vague ideal. Therefore, Cushing recommended direct work with and choice by the individual with I/DD regarding community. My community engagement proposal would be collaborative between the local county board of I/DD and individuals with I/DD and would aim to increase community inclusion based on each individual's personal desires. Every individual would get to define what community group they would personally like to participate in and choose parameters around that participation (for example, one person might choose a monthly book group and another person might choose going to a yoga studio for classes three times weekly).

### ***Beyond Presence and Toward Participation***

Cummins and Lau (2003) highlighted the difference between community presence and community participation. They noted that often individuals with I/DD can be *present* in their community, but they are often not fully included a part of activities. They emphasize the ideal of moving beyond *presence* alone and toward *participation*. Similarly, Bigby (2008) noted the concern that individuals with I/DD, even those who do visit different places in their community, are often not known by others. The goal for this initiative is for individuals with I/DD to not just be present or visit places in their community, but to choose a desired activity and engage on a regular basis for a year of time to more fully participate and, ideally, experience inclusion.

A consistent theme throughout the literature on community inclusion for individuals with I/DD is that a way to achieve community inclusion is difficult to develop due to differing definitions and desires regarding inclusion. However, this initiative has

the chance for success because it focuses on individual desires. Additionally, the initial focus is with a small group to identify and work through barriers to participation. If success can be achieved for individuals within that group, the initiative can be expanded to a larger group.

### ***Community Participation and Friendship***

In my multi-faceted proposal, I present recommendations regarding additional research regarding deinstitutionalization, community engagement, friendship, and satisfaction based on residence, research to identify the best ways to collaboratively build friendships for individuals residing with family, and community engagement opportunities for individuals in a variety of residential situations. For all proposed solutions, my hope is that community participation will increase friendship development and vice versa or that the two constructs can be shown to increase side by side. Friedman and Rizzolo (2018) noted a correlation between community interaction and participation by individuals with I/DD and individuals with I/DD who had strong friendships in their life. They detailed that friendships and community interaction most likely have a cyclical effect as friendships present more opportunities for community engagement and greater participation within one's community increases the opportunity to develop and build friendships. It is my hope that these initiatives will result in greater friendship satisfaction as well as increase community participation opportunities.

### **Evidence that Challenges the Proposed Solutions**

Friendship and community inclusion are not one-way streets. While individuals with I/DD may be interested and ready to build friendships or fully participate in their community, community members may not be prepared to engage as friends or invite and



include individuals with I/DD in community activities. Additionally, many individuals with I/DD rely on support services for care. Increased friendships, community participation and inclusion may not be able to occur if the necessary support services are inconsistent or do not assist with achieving an individual's goals.

### *Community Preparedness*

For these initiatives to be successful, community members that are a part of the activities chosen by participants will need to be open to welcoming and engaging individuals with I/DD into community groups. Van Alphen et al. (2010) conducted a survey of neighbors of individuals with I/DD in Norway and identified that multiple respondents expressed apprehension toward engaging with individuals with I/DD and many respondents stated that they tended to interact with a staff member of an individual with I/DD over a direct interaction with the individual with I/DD. Additionally, McLean et al. (2017) noted significant hesitation by young people in Moldova regarding increased integration of and interactions with individuals with I/DD in the community. They specifically noted that negative social attitudes create obstacles to equality and inclusion within communities for individuals with I/DD. I will make sure to regularly discuss any concerns resulting from a lack of full inclusion by community members, both regarding friendship and community engagement, and brainstorm how to overcome those obstacles.

Bigby, Bould, and Beadle-Brown (2017) highlighted that even individuals with I/DD that were involved in community activities often experienced loneliness and struggled to feel included. Those experiences highlight the need for community members to be engaged as a part of the process; to interact with the individuals participating in these pilot projects rather than just allow them to be present.

### *Supports to Achieve Success*

Clement and Bigby (2009) spoke to the number of individuals with I/DD that relied on support staff for assistance in daily life. They emphasized that staff who are supporting individuals with I/DD must be aware of desired outcomes and the importance of those outcomes for the outcomes to be achieved. For these initiatives, whomever an individual relies on for transportation or supports within a community, staff, friends, or family, will need to be aware of the desired goals for the individual regarding the initiatives. That support will also need to be on board with assisting in any ways needed to achieve the desired goal regarding friendship or community participation.

### **Implementation of the Proposed Solutions**

This solution includes multiple proposals that have not yet been presented to or approved by a local county board of I/DD. Recruitment for participants will be sent out through that board to all individuals with I/DD and guardians, as applicable. Recruitment could be sent for each separate proposal through a mass mailing and email and could be sent to all individuals connected with Support Administration at the county board as well as individuals residing in institutional facilities throughout the identified county for the satisfaction survey and community engagement initiatives and to individuals residing in family homes for the proposed friendship initiative. If interested in participating in the identified and applicable initiative, individuals will commit to engaging in the survey or set guidelines of the initiative. As an incentive to participate, the local county board will provide incentives to complete the survey or ensure needed services and supports are in place to participate in the friendship or community engagement initiative.

**Additional Details for Community Engagement Proposal**

As the community engagement initiative is individualized, supports for such will vary from person to person, but could include staff time and attention, transportation, agreed upon funds to offset the cost of the chosen activity, etc. Interested individuals will submit a short application and summary of their chosen activity. Applicants will then be divided into three categories: family home, community home, and institutional home. Four applicants will be randomly selected from each of the three categories. I will then work with the individual as well as any of their personal team members to ensure that they are able to move forward and engage in their chosen activity. At the start of the initiative, I will gather baseline data from each individual regarding community participation, community inclusion satisfaction, and friendship satisfaction. I will collect qualitative information from the individual and their team monthly to assess for engagement, inclusion, barriers to participation, and friendships that may result from their chosen activity. In addition to collecting information about barriers to participation, I will work with the individual and team to address any barriers so that engagement is able to continue as smoothly as possible. The same quantitative questions that were asked of individuals to collect baseline data will be collected quarterly throughout the year.

I will be able to assist the local county board of I/DD to implement personalized community engagement opportunities on a larger scale following the pilot of this initiative. The overall collection of information, both qualitative and quantitative, throughout the year-long pilot, along with the specific work to overcome barriers to participation for the 12 initial individuals that are a part of the pilot program, will provide information that I can utilize to ensure success for others in the future.

### **Factors and Stakeholders Related to the Implementation of the Solutions**

The identified local county board of I/DD will need to support these proposals for them to move forward. Individuals with I/DD, families of those individuals, and staff that provide support of those individuals are also key stakeholders for these initiatives to be successful. For the community engagement proposal, community partners, specifically community members that are a part of any identified and preferred community groups chosen by individuals with I/DD to join, are also an integral component to this program.

As the leader implementing these initiatives, I will aim to keep the desires of the individuals participating at the forefront of all planning. Northouse (2013) spoke on the need for an Authentic Leader to be both transparent and responsive. I want to be clear about the goals of each initiative – assess satisfaction in the identified areas based on deinstitutionalization and residence, assess and identify barriers to friendship for individuals residing in family homes, and increase community participation for individuals with I/DD based on their chosen activities as well as overcome barriers that get in the way of community inclusion. I want to also be responsive to what is working and what is not working as a part of each proposal and therefore be flexible if there is a need to adjust the survey or the initiative.

Throughout implementation of these initiatives, I will continue to be flexible to meet the needs of the individuals that participate. Support systems are already set up around most individuals connected with local county boards of I/DD, whether that be support staff from a provider agency, ancillary staff through the board (*i.e.* nursing, behavioral health, speech and language, assistive technology, occupational therapy, etc.), friends, or family. I will rely on the supports that are already in place. Sheth et al. (2019)

identified that some of the most significant barriers to friendship and community engagement for individuals with I/DD were transportation and access (necessary staffing, funds) to activities. However, I am also hopeful that the identified county board will support these initiatives by putting extra funding in place as necessary to assist individuals to meet desired outcomes.

### **Evaluating the Outcome of the Proposed Solutions**

#### **Survey**

Simplican et al. (2015) emphasized the need for a universally agreed upon definition of social inclusion. Putting together and administering a survey requires solid operational definitions regarding assessed constructs as well as validity and reliability that meet traditionally acceptable standards. Additionally, it will be important to have a large enough sample size to provide comparison information based on residence, especially as the small sample size of individuals residing in an institution were a concern for this research study. Otherwise, typical research protocols and ethical standards are important to follow as a part of this proposed solution.

#### **Seeing One's Friends While Residing in a Family Home**

My initial proposal regarding friendship begins with gathering information from individuals residing with family members as well as those family members. Therefore, typical research protocols and ethical standards would need to be followed as a part of this proposed solution. The next step to this proposal would be to put supports or services in place to improve satisfaction within the area of seeing one's friends – at this step, it would be critical to evaluate whether the supports and services put in place led to an increase in seeing one's friends for the individuals that are a part of the initiative.

## **Community Engagement**

As noted above, evaluation will occur throughout the year-long pilot. I will gather baseline data from each of the 12 participants at the start of the program, and then assess the same quantitative questions quarterly. I will also speak with individuals and teams monthly to gather general information, specifically including barriers to participation and increased additional community opportunities and friendships. I will need to be flexible as information is gathered, and there may be a need to adjust based on each individual situation or adjust the pilot for all participants if community participation is not being achieved as planned and desired. The baseline, monthly, and quarterly evaluations will assist to then implement the program on a larger scale.

## **Implications**

### **Practical Implications**

In his research, Salkever (2000) found that, for individuals with I/DD, the lowest levels of community engagement correlated with the lowest levels of life satisfaction. Bigby (2008) highlighted significant barriers regarding building and maintaining friendships for individuals with I/DD. Additionally, Verdonschot et al. (2009) identified that even if individuals residing in community settings had greater levels of community engagement and friendship satisfaction than those residing in an institutional facility, overall individuals with I/DD had significantly lower levels of community engagement and friendship satisfaction than the general population. Sheth et al. (2019) identified that individuals with I/DD, no matter their residential situation, faced considerable barriers regarding community participation.

Both the friendship initiative and community participation initiative have the practical implications of identifying and breaking through friendship and community participation barriers and advancing community engagement and social inclusion for individuals with I/DD. Pilot projects such as these cannot be found in the existing research and literature. Therefore, it has the possibility of adding valuable real-world information regarding friendship and community participation for individuals with I/DD to the existing base of data and knowledge. In addition to that specific information, the potential cyclical connection between community participation, community opportunities, and friendship satisfaction (Friedman & Rizzolo, 2018) can be further verified. If this endeavor is a success, the identified pilot county can become a model for other communities around the country and world.

### **Leadership Theory and Implications for Future Research**

Considerable research has focused on quality of life and community and social inclusion based on residence due to deinstitutionalization (Chowdhury & Benson, 2011; Hamelin et al., 2011; Jones & Gallus, 2016; O'Brien et al., 2001; Tamas et al., 2016). However, as the analyses from this research did not identify significant statistical differences in community engagement and friendship for individuals with I/DD based on residence, it appears critical that researchers begin to focus on how to improve community engagement and friendship regardless of where one resides. It would be best for that research to take a Transformational Leadership approach (Northouse, 2013) and be a true collaboration between individuals with I/DD and the leaders who seek to implement improvements regarding community and friendship. Too often individuals with I/DD have been kept out of research altogether. There is opportunity for leaders to

incorporate the personal outcomes and desires of individuals with I/DD; for the research to be conducted with and not about such individuals.

Additionally, there is benefit to additional research regarding increasing friendship opportunities for individuals residing in family homes. As noted through the literature review, considerable research has been conducted on individuals residing in institutional or group homes, leaving a lack of research on individuals with I/DD who reside in family homes. It would be beneficial to gather information both from individuals with I/DD as well as family members regarding how friendship satisfaction as well as community inclusion and satisfaction can be increased for individuals residing in family homes.

### **Summary of the Dissertation in Practice**

This analysis provided an overview of the deinstitutionalization of individuals with I/DD, specifically the second wave of deinstitutionalization in the state of Ohio that was initiated by Disability Rights Ohio. A review of the literature identified conflicting findings regarding deinstitutionalization and satisfaction. Some researchers found a lack of significant differences in satisfaction based on residence following deinstitutionalization (Francis et al., 2014; Lucas-Carrasco & Salvador-Carullo, 2012). Others did find positive quality of life outcomes following a move from an institution to a community home (O'Brien et al., 2001). However, researchers did identify a positive correlation between life satisfaction and community engagement (Cummins & Lau, 2003; Salkever, 2000) and quality of life and friendship (Friedman & Rizzolo, 2018). Therefore, I conducted an exploratory quantitative data analysis, utilizing data collected from the Ohio NCI Study in 2017-2018 (National Core Indicators, 2017-2018) to identify



differences in community engagement and friendship based on residence. However, my analyses revealed no statistically significant differences in community engagement or friendship for individuals with I/DD, based on residence, institutional versus community or family versus group home. Therefore, I outlined proposals to gather additional information regarding community engagement and friendship, including satisfaction measures, based on residence, to gather additional information regarding seeing one's friends for individuals residing in family homes, and to increase community participation for individuals with I/DD, regardless of residence. If successful, my proposed solutions will pave the way for leaders in the field of I/DD to work collaboratively with individuals with I/DD to achieve personal community engagement and friendship outcomes.

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## Appendix A

### Creighton Institutional Review Board Approval



Office of the Provost  
Research Compliance

|                         |   |
|-------------------------|---|
| <b>DATE:</b>            | 21-Oct-2020   |
| <b>TO:</b>              | Whitesel, Candice   |
| <b>FROM:</b>            | Social / Behavioral IRB   |
| <b>PROJECT TITLE:</b>   | <b>COMMUNITY INCLUSION AND<br/>FRIENDSHIP SATISFACTION FOR<br/>INDIVIDUALS WITH INTELLECTUAL AND<br/>DEVELOPMENTAL DISABILITIES BASED<br/>ON TYPE OF RESIDENCE IN THE STATE<br/>OF OHIO</b> |
| <b>REFERENCE #:</b>     | 2001419   |
| <b>SUBMISSION TYPE:</b> | Not Human Subjects  |
| <b>REVIEW TYPE:</b>     | Administrative Review   |
| <b>ACTION:</b>          | Acknowledged  |

Thank you for your submission of Initial Application materials for this project. The protocol attached to this submission has been reviewed.

It has been determined this project does not involve human subjects under 45 CFR 46.102(f). IRB review is not required.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact the IRB Office at 402-280-2126 or [irb@creighton.edu](mailto:irb@creighton.edu). Please include your project title and number in all correspondence with this committee.

#### Institutional Review Board

☎ 402.280.2126 | ☎ 402.280.3200  
Dr. C.C. and Mabel L. Criss Health Sciences Complex I  
2500 California Plaza Omaha, NE 68178

[creighton.edu](http://creighton.edu)  
[creighton.edu/researchservices/yourcommittees/irb](http://creighton.edu/researchservices/yourcommittees/irb)

## Appendix B

### Ohio State Institutional Review Board Approval

Protocol Number 2020-48  
Original Review 12/1/2020  
Continuing Review

**THE OHIO DEPARTMENT OF HEALTH  
HUMAN SUBJECTS INSTITUTIONAL REVIEW BOARD**  
*(FW:100001963, IRB00002180)*

**ACTION OF THE REVIEW BOARD  
(CERTIFICATION)**

With regard to the employment of human subjects in the proposed research entitled:

**ODH IRB 2020-48: "Community Inclusion and Friendship Satisfaction for Individuals with Intellectual and Developmental Disabilities Based on Type of Residence in the State of Ohio"**

CDC of HHS Federal Project Number (if any):

Principal Investigator: Candice Markle

Agency: Creighton University

The Institutional Review Board has taken the following action:

- |                                     |             |                                     |                   |                          |                           |
|-------------------------------------|-------------|-------------------------------------|-------------------|--------------------------|---------------------------|
| <input checked="" type="checkbox"/> | Approved    | <input type="checkbox"/>            | Expedited Review  | <input type="checkbox"/> | Waiver of Written Consent |
| <input type="checkbox"/>            | Disapproved | <input checked="" type="checkbox"/> | Full Board Review | <input type="checkbox"/> | Exempt                    |
| <input type="checkbox"/>            | Tabled      |                                     |                   |                          |                           |

Requirements:

Any publication resulting from the approval of this protocol must state the following "This study includes data provide by the Ohio Department of Health which should not be considered an endorsement of this study or its conclusions."

**This application has been approved for the period of one (1) year and will expire on November 30, 2021.** Renewals are the sole responsibility of the principal investigator. No reminders will be sent.

Additionally, it is the responsibility of the principal investigator to:

- 1) obtain approval before making procedural changes;
- 2) maintain the confidentiality of the research participants' identities; and
- 3) retain a copy of each signed consent form for at least three (3) years beyond the termination of the subject's participation in the proposed activity.

Date: December 1, 2020

Signed: \_\_\_\_\_



CC: Investigator, Division Chief/Bureau Chief