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Successful Aging: Growing Older with a Developmental Disability

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### Abstract

The purpose of this interview study was to: 1) observe reoccurring themes related to aging in individuals with intellectual and developmental disabilities (I/DD), 2) review areas of matter including health, and occupational areas, 3) collect personal perceptions of adults with I/DD on growing older, and 4) give occupational therapists clinical implications for meaningful and purposeful interventions to improve quality of life and lifespan of individuals with I/DD. There were 13 consenting participants in this study who all accepted being interviewed, were willing to discuss their thoughts on aging, and lived in a community-based residential home or facility. During individually recorded interviews, participants answered a demographic questionnaire developed for this study as well as an interview guide that was read aloud by the researchers. Three researchers were involved in a step-by-step data analysis process. Once data was collected, the researchers discussed common themes discovered and interesting findings from the recorded interviews. The current study provided preliminary evidence focusing on the perceptions of adults with I/DD on aging successfully in place as well as implications for occupational therapy with this growing population.

### Successful Aging: Growing Older with a Developmental Disability

Researchers and clinicians have indicated that there is a significant increase in the number of aging adults with intellectual and developmental disabilities (I/DD) (Hahn, 2012). It has been suggested that addressing their growing needs may enhance and assist in developing the question of what older adults with I/DD feel they need in order to age successfully.

Unfortunately, there is limited research on what older individuals with I/DD feel that they require in order to age successfully in place. In an attempt to uncover these needs, the present study examined common themes associated with successful aging with I/DD and what occupational therapy can do to assist with these needs. To understand the present study, a brief review of past research on the growing needs and key challenges of aging individuals with I/DD will be presented as well as the role of occupational therapy in assessing these individuals with aging. The therapeutic benefits of meaningful activity will be discussed following an explanation of the present study.

Recent studies have provided the baseline needed to support justification for the current study. In a study on autism spectrum disorder (ASD), Piven and Rabins (2011) emphasized the need to understand how disabilities and dependencies that result from aging interact with those individuals. He also emphasized how the growing influx of older adults with ASD could impose large humanistic and economic burdens on the healthcare system and society without having an understanding of the aging process with a developmental disability. Heller, Stafford, Davis, Sedlezky and Gaylord (2010) provided an overview of growing needs and key challenges of those growing older with a developmental disability. Salvatori, Tremblay, and Tryssenaar (2003) gave personal perspectives from individuals with developmental disabilities as well as

their family members and service providers on day-to-day experiences and overall quality of life in older adults with developmental disabilities. The rationale behind this study is that individuals with I/DD are a quickly aging population, and as medicine advances, they are undoubtedly living longer lives. Unfortunately, there is very little research that supports how the perceptions of older individuals with I/DD is useful in promoting successful aging within this population.

### **Demographics**

Aging is something many of us will go through at some point in our lifetime. As older adults, many of us will understand what crucial necessities we will need in order to age successfully. Increasing age is but one of many factors associated with disparities in health access and outcomes, along with sex, nonwhite race, lower socioeconomic status, geographic proximity to health professionals, and having a disability. Moreover, within the population of those with disabilities, persons with I/DD are further disadvantaged (Perkins & Moran, 2010). Aging with a disability can make life more perplexing. There is an estimated 641,000 adults over the age of 60 with I/DD in the United States, and over the next 20 years, their numbers will double as the “baby boomers” reach retirement (Engquist, Johnson, & Johnson, 2012). For individuals with I/DD, the transition into older adulthood is a process that can be uncertain and misunderstood. According to the Centers for Disease Control and Prevention (2011):

Developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person's lifetime (para. 9).

From the 1950's to 2007, the average lifespan for the general population has grown from an average of 68 years to 78 years. In adults with I/DD, life expectancy has also grown from the mid-50 to the early 70's (Heller et al., 2010). Because of this increase in life expectancy of individuals with I/DD, there are several areas of concern including health and occupational areas.

### **Areas of Concern**

Areas of concern for aging adults with I/DD include a variety of health factors including fall risks, and occupational areas including housing, work, mobility and socialization. In addition, older adults with I/DD have a higher chance of developing chronic health conditions, especially at younger ages (Havercamp, Scandlin, & Roth, 2004).

In a study by Havercamp et al. (2004), researchers examined the health status differences of individuals with I/DD compared to individuals without I/DD. They found that when compared to the general population, adults with I/DD were more likely to have fair to poor overall health status (Havercamp et al., 2004). People with I/DD were less likely to utilize medical care services including cervical and breast care screening and oral health services (Havercamp et al., 2004). Women with I/DD were significantly less likely to have had routine cervical and breast cancer screenings than women without I/DD. Likewise, 11.5% of women with I/DD reported that they had never visited a gynecologist (Havercamp et al., 2004). In addition, people with I/DD were more likely than those without I/DD not to have had their teeth cleaned in the past five years or at all in their lifetime (2004). The rate of diabetes was significantly higher in adults with I/DD although the diagnosis of arthritis was notably lower in people with I/DD (Havercamp et al., 2004). Additional health complications stemming from poor nutritional habits in some individuals with I/DD include obesity, and low bone mass density (Jasien, 2012). Moreover, falls are among the most common cause of health decline in older adults with I/DD. (Heller et al.,

2010). All of these areas of health could pose as a major concern for individuals with I/DD, and increased awareness of these complications may result in a longer lifespan and better quality of life.

According to Salvatori et al. (2003), many adults with I/DD talked about various health problems; however, most of them were not complaining about deteriorating health or were particularly concerned about growing older. As one participant stated, "If I get old, that's fine with me as long as I have health to do something." On the contrary, family members voiced concerns about the health of their aging children as well as their own aging and related issues of caregiver burden. This raises questions as to whether or not individuals with I/DD are aware of the complications that come with aging as well as precautions that they should understand.

Physiological health issues impact successful aging, but research has shown that falls significantly contribute to health declines in older adults with I/DD. Falls are one of the most common causes of health decline in older adults. In a study of older adults with I/DD and falls, Grant, Pickett, Lam, O'Connor, and Ouellette-Kuntz (2001) explained that falls are a frequent and reoccurring health issue. This is alarming because the existence of a developmental disability alone puts these individuals at risk for traumatic injury (Grant et al., 2001). Characteristics that pose as risk factors for falls can include maladaptive behaviors, altered pain thresholds, pain insensitivity or indifference, and seizures (2001). In addition, epilepsy is associated with injuries including fractures. Individuals with epilepsy and I/DD have a higher mortality rate due to sudden death, aspiration, and pneumonia (Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2000). Inadequately treated seizures can further impair cognitive function (2000). All of these conditions can contribute to increased risks for falls and negatively impact occupational areas.

### **Occupational Areas**

Some occupational areas of concern with aging adults with I/DD are their living environment, work environment, mobility, and socialization. These are areas that are considered “typical” to many in the general population; however, they can pose as a concern for those with I/DD. Housing and supervision is one of the most common concerns for adults with I/DD.

Older adults with I/DD and their caregivers want housing and support that help them maintain and enhance their social networks with their peers as they grow older. Social supports and formal housing are important during transitional phases in the lives of individuals with I/DD to be able to successfully age in place (Shaw, Cartwright, & Craig, 2011). In addition, aging in place allows older individuals to stay connected to their support systems, friends and communities (Engquist et al., 2012). People with mild I/DD, who live in the general community with minimum support, can often adopt unhealthy lifestyles and poor health habits thus leading to potentially risky behavior that contributes to later-life health or social problems (Meijer, Carpenter & Scholte, 2004). Though support services are more than beneficial to older adults with I/DD, they still want to feel that they have some control in their own life. According to an older adult with I/DD, "Like we don't want a supervisor...you want to be like those people across the street that live by themselves" (Salvatori et al., 2003). Individuals with I/DD do not want to feel institutionalized but, instead, comfortable within their housing arrangements, and if possible, mobile.

Mobility is not only a major issue for all aging adults in the general population, but especially for adults with I/DD because of its key role in traveling to important locations including the doctor, family, friends and other places of interest. Only 61.7% of adults with I/DD reported being able to see family members whenever they desired (Havercamp et al., 2004). Transportation posed a significant barrier to spending time with friends for about 18% of these



adults (2004). In a mobility skills training program for adults with I/DD, twenty-nine adults with I/DD were trained by an occupational therapist to use city transportation for leisure and recreation. After treatment, they were able to provide their own recreation by independently traveling via public transportation (McInerney & McInerney, 1992). Being able to get to places that are meaningful can be a motivating factor in allowing for more mobility and socialization for persons with I/DD and taking stress off of their equally aging caregivers. Being mobile allows for more independence and a better quality of life, and also the ability to attain a job and allow for more social interaction.

The work environment not only provides a means of income and independence, but also socialization and support. Because many aging individuals with I/DD are unemployed/underemployed with little to no pay, the thought of retirement has a different meaning than it does for older adults in the general population who have been employed for most of their adult life (Engquist et al., 2012). Many older adults with I/DD work simply because of the need for ongoing socialization and support (2012). A study conducted by Buys et al. (2008), found that in terms of working, individuals with I/DD wanted to 'keep on keeping on'. That is, despite reaching older age, most wanted to maintain their routines, keep active, and keep doing things in life, which interested them. Retirement was generally not something they thought about. In an interview, one individual with I/DD stated "Me having money. I like to have stuff. I got money but it isn't enough" (Salvatori et al., 2003). This individual understood that being able to have one's own money provided a way to purchase the things that he/she desired, which, in turn, made him/her happy.

Siporin and Lysack (2004) found that workers with I/DD tended to experience limited non-work task social interaction with their nondisabled counterparts and reported little

interaction and friendships outside of the workplace. The advantage of receiving community level support is that even if one person leaves the work, the support is still there. This may be of particular importance for people who have problems remembering individual names, or developing personal relationships (Lunsky, 2008). Within supported employment environments, new social relationships between individuals with disabilities and their coworkers without I/DD are anticipated (Siporin & Lysack, 2004). Overall, work provides a sense of financial awareness and liberation as well as a great place for socialization.

Socialization for adults with I/DD varies from person to person. Individuals with I/DD are more likely to be residing with parents into adulthood and have more limited social supports and friendships outside of their family networks (Heller et al., 2010). Seventy-five percent of people with I/DD live with families, and more than 25% of family caregivers are over the age of 60 years. Another 38% are between the ages of 41-59 years old. Salvatori et al. (2003) found that few adults with I/DD stated that their relationships with others were entirely satisfactory or rewarding. They continuously identified the desire for more social outings, friends and intimate relationships. Some shared negative memories about their past experiences involving physical and sexual abuse. According to one individual with I/DD, "Try to understand that people are lonely and all that stuff. My parents don't understand, the staff don't understand" (Salvatori et al., 2003). A need exists for aging adults with I/DD and their relatives to have access to quality resources that address their age-related health and social changes (Heller et al., 2010). Health and occupational factors are vital areas in successful aging in older adults with I/DD. Recently, individuals with I/DD have begun to give personal input on what it is like to age with a disability in hopes of uncovering ways to make the aging process successful.

### **Aging Successfully with I/DD**

Caregivers and family members are the main sources of information when it comes to meeting the necessities of older people with I/DD. Little research is present on what individuals with I/DD want for themselves in order to age successfully. In a personal account of living with cerebral palsy, a 67-year-old woman highlighted some of the effects of aging with a developmental disability (Jones, 2009). She emphasized that as people with I/DD age, prevention of functional decline and further disability forms the substance for a beneficial quality of life and a sense of individualized well-being. She mentioned that achieving maximum health requires a synthesis between adults with I/DD and their healthcare provider, which is built on respect and communication (Jones, 2009). Fortunately, this woman was not only aware of her specific needs, but what could be done about it so improve her quality of life.

According to the North Carolina Institute of Medicine (2009), there are three main criteria of successful aging developed by researchers which include: the reduction of disease and disability, the maintenance of high cognitive and physical functioning, and active engagement in life. As suggested by this framework, many Americans relate good health, independence, relationships with friends and family, physical health, and staying connected to the community as indicators of successful aging. Furthermore, like all older individuals, people with I/DD desire to have a successful aging experience. However, for numerous reasons, these goals may be more difficult for individuals with I/DD than for the general aging population (NCIOM, 2009).

Not all aging adults with I/DD may be aware of the tools they need in order to live a more functional lifestyle although they may know what they specifically desire on a day-to-day basis. Salvatori et al. (2003) noted that many adults with I/DD expressed little concern regarding the future. This could be because of their core concrete orientation to the here-and now, and/or their overall satisfaction with their personal lifestyle and living arrangements. This is an issue

because all individuals should be aware of what they need and can do to have a better quality of life. Accordingly, occupational therapy interventions can provide individuals with I/DD the roadmap they need to age successfully in their own environment.

### **Role of Occupational Therapy with Adults with I/DD**

In the past, occupational therapy services for adults with I/DD were not readily available within the community (Siporin & Lysack, 2004). But recently the concept of livable communities and healthy homes has been promoted for people who are aging with disabilities (Heller et al., 2010). Occupational therapy specializes in adapting environments to adjust to the personalized lifestyle of an individual through the implementation of environmental interventions (EI) and assistive technologies (AT). EIs consist of adapting or modifying the home or living environment and ATs have portrayed positive effects on function. Environmental interventions and assistive technologies help to improve or maintain function in adults I/DD. For older adults with I/DD, the big challenge stems from families and service providers trying to adapt the environments (Heller et al., 2010). Although occupational therapists are skilled at assisting with functional adaptations for individuals, they can also assist with the promotion of health and wellness in older adults with I/DD.

Individuals with I/DD living in a community need access to supportive care providers and skilled healthcare clinicians who are knowledgeable about the person, the condition of the individual, and the services and supports available to them (Long & Kavarian, 2008). The goal of occupational therapy is to maximize a person's independent functioning, and it is obligatory upon occupational therapists to recognize the risk factors that can affect activities of daily living (Walker & Howland, 1991). In a report of the 2001 Invitational Research Symposium on Aging with Developmental Disabilities, Heller, Janicki, Hammel & Factor (2002) addressed three areas

of focus that contribute to the promotion of healthy aging and wellness of individuals with I/DD including mind-body interactions, promotion of nutrition, and promotion of physical activity. In mind-body interaction, the goal is to identify key risk factors for disease that come from this interaction. In promotion of nutrition, one is promoting a healthy, active lifestyle throughout their lifespan. Lastly, physical activity includes any physical activity, but particularly balance and coordination exercises to prevent falls through exercise (Heller et al., 2002). These are all factors that occupational therapists can incorporate into a health and wellness program for older adults with I/DD. One of the best ways for occupational therapists to make these goals functional and accessible to individuals with I/DD is to make sure that they are meaningful to the individual.

Salvatori et al. (2003) stated that meaningful activity was a common theme among individuals with I/DD. Service providers were most concerned about the need for appropriate education opportunities, employment options, leisure and retirement programs, and transportation access. Although all adults with I/DD experienced some form of meaningful activity, most activities were leisure-related (Salvatori et al., 2003). One older adult with I/DD said, "I go for walks. I ride my bike. I go to the [retirement] program." Occupational therapists can take these interests, and turn them into meaningful, therapeutic interventions and incorporate them into an individualized treatment plan for an older adult w/ I/DD in an effort to help them age successfully.

### **Current Study**

In the current study, researchers focused on the perceptions of older adults with I/DD on what they feel they needed in order successfully age. Researchers also explored what clinical implications their responses could have for occupational therapy. There is little research on what

individuals with I/DD feel that they need, personally, in order to age successfully; however, the Salvatori et al. (2003) study serves as a reference point as to what older adults with I/DD are perceiving when it comes to their own aging.

As just reviewed, people with I/DD are aging at a rapid rate and are living longer lives than ever before. Tackling their evolving needs may assist in answering the question of what the perceptions of older adults with I/DD are on aging successfully and what the role of occupational therapy can do in helping them age successfully. In an effort to discover these needs, the researcher identified the following questions:

- What are reoccurring themes related to aging with I/DD?;
- What are the perceptions of older adults with I/DD in areas of matter including health, and occupational areas?;
- Because research is so limited, what do individuals with I/DD feel they need, overall, in order to age successfully?;
- What are clinical implications for meaningful and purposeful interventions to improve the quality of life of individuals with I/DD?

## **Method**

### **Participants**

The target population for this study included 13 males and females, 40 years and older who had an intellectual or developmental disability (I/DD). All of the participants lived in community-based residential homes or facilities, accepted being interviewed, and were willing to talk about their thoughts on getting older. The study was conducted in the participants' residence at Sunshine Communities Inc., and participants were chosen with the assistance of staff at Sunshine Communities Inc.

Individual interviews were conducted with each participant over a fourteen-month period from September 2013 to November 2014. Interview sessions did not exceed a two-hour time limit, and if the participant was not up for his or her interview on his or her given day, the researchers had the option to re-interview. Participants did not receive any financial compensation for participating in this interview.

***Demographic Questionnaire.*** The questionnaire developed for this study included open-ended questions that encouraged answers on a variety of topics including information on their place of residence and status of family members (see Appendix A for questionnaire). In addition, participants were asked to answer questions as openly and honestly as possible. The interview questions were developed to allow participants to openly share their opinions on what their individual needs were. No reliability or validity measures are available for this tool.

***Interview Guide.*** An interview guide was used so that the interview would be conducted in an organized and timely fashion. According to Patton (2002), an interview guide is designed to create a systemic and comprehensive interview for all participants by providing topic areas to be explored. Each answer given by a participant was subject to a follow-up question or comment for reiteration or further exploration (See Appendix B for interview guide). No reliability or validity measures are available to this tool.

## **Procedure**

The author functioned as the interviewer and collected all of the data from the interviews. Assistance was given from advisors that were experienced in conducting interviews. The interview sessions were conducted in the houses of residents or service recipients, or in private rooms on the Sunshine Inc. campus that were allotted for this study. The researchers made sure that the setting was reserved and free from distractions in preparation for the interviews.

Once researchers arrived to the participant's place of residence or meeting location, they greeted subjects and asked them to complete an informed consent form prior to beginning the interview process if they were their own guardian. If participants were not their own guardian, then their appointed guardian was asked to fill out an informed consent form and the participant filled out an assent form. Researchers briefed participants on the study and participants made the decision to sign the forms and participate in the study. Then, each participant and/or guardian received a copy of his or her signed consent form for his or her own safekeeping. Next, participants who agreed to partake in this study were provided with an overall explanation of the study at the beginning of the interview. The researcher then read a demographic questionnaire to participants and filled in the participant's responses. Demographic questions covered information such as participant's diagnoses, age, gender, living arrangements, and family status. Following the demographic questionnaire, the researcher verbally read the interview questions to participants, and offered clarification when needed. To maintain participant's focus and attention, each interview did not exceed a time limit of 2 hours, and informal conversation was encouraged. An audio tape recorder was used to record each interview session from beginning to end. At the conclusion of each interview, researchers thanked participants for their time and participation, and the researcher categorized the recordings with the participant's pre-interview materials. The recorded tapes and participant information were stored in a secure cabinet.

### **Results**

The data analysis of this study followed a series of steps to organize the information collected from participants (Portney & Watkins, 2009). Data analysis began with three researchers reviewing and breaking down the participant responses on the interview questions.



Researchers then decided if further exploration was needed. The participants' statements were categorized by questions and analyzed individually.

The goal of early analysis stage for the interviewers was to use raw data to form a variety of participant statements from the interviews. The researcher analyzed the data independently, collectively and independently again. This allowed researchers to develop a coding system and apply them to data collection.

Researchers implemented the following stages:

- 1) Each researcher explored interview transcripts. This gave researchers an idea of major concerns of participants, and each researcher then decided what answers they found significant and a major contribution to research.
- 2) All three researchers met through a conference call and discussed the topics and key points they found significant, and analyzed as many interviews as possible during time allotted for the meeting.
- 3) The researcher worked individually to take the information that the three researchers collectively found, and categorized the major themes.
- 4) All three researchers met again through a conference call to discuss what the researcher decided to incorporate. The researchers provided constructive feedback on the findings, and the researcher made revisions as needed.

This study consisted of 13 participants ranging in age from 42-79 years ( $M = 57$ ,  $SD = 11.01$ ). Participants provided background demographic information regarding their current age, gender, health, family and living arrangement statuses. Out of the 13 participants, 10 were male (77%) and three were female (23%). In addition, participants were asked what diagnoses they currently have or take medication for, and the top responses were: 1) high blood pressure (38%),

2) diabetes (31%), 3) seizure disorder (31 %), visual disturbances (15%), and high cholesterol (15%). Furthermore, five out of the 13 participants (38%) reported living alone with some assistance from Sunshine Inc. staff. In addition, eight out of the 13 participants (62%) reported living with a sibling or roommate(s). Only one out of the 13 participants reported having parents who were still living. Finally, participants were asked how long they have resided in their current homes with the shortest amount of time being one year, and the longest, 10 years ( $M = 5$ ,  $SD = 3.02$ ).

After thorough analysis of personal interview transcripts, four overarching themes related to participant's perceptions of successful aging with I/DD were identified including: health and aging, socialization, employment, and overall life satisfaction. The first theme of health and aging consisted of four subthemes including: overall health, aging concerns, health and fitness and falls. The second theme of socialization consisted of four subthemes including: socialization within the workplace, social outings, family involvement, and importance of staff. The third subtheme of work included two subthemes including: job satisfaction and retirement. Finally, the fourth theme of overall life satisfaction included three subthemes: aging in place, barriers to successful aging, and meaningful activities. Quotations from participant interviews will assist in illustrating the themes from the participant's perspectives. Within these quotes, information in brackets [text] has been added for clarification, and ellipses (...) show where trivial items have been omitted from the original passage. There is no level of importance in the ordering of themes.

### **Health and Aging**

All participants demonstrated personal insight into health and aging. The majority of participants reported a variety of health complications, as documented in the demographic

questionnaire, but most of them did not complain of declining health, nor were concerned with growing older. Comments also reflected perceptions on health and fitness and falls as they relate to aging in place. All of these reports contribute to various aspects of health and aging. When asked about the meaning of growing older, one participant replied:

“Getting older is really a...it’s just a process of life that, that you live. It’s not like getting old, it’s like how you live your life and the way you live it.”

**Overall health.** The theme of overall health was reflected in many participant’s statements as being significantly well, even with former and current health complications. Interestingly, when asked how the participants felt about their overall health, 11 out of 13 (85%) reported perceiving themselves as having good health. One participant said:

“I’m basically healthy. I was in the hospital last year over a kidney failure. But other than that, I’m healthy.”

Another participant stated:

“I would say it’s in between fair and good. Sometimes my sugar’s high. Depends on what I eat. Yeah. So I’m not saying it’s 100% good, but it could be better.”

A third participant with diabetes added:

“...I’m doing pretty good eatin’...So I’m doing pretty good.”

Finally, a participant with cerebral palsy expressed feelings of declining health stating:

“Poor health...Aging and I have cerebral palsy.”

**Aging concerns.** Intriguingly, the majority of participants could not explain what getting older meant for them, or had concerns about growing older. Participants were asked if they had any general concerns about growing older. One participant said:

“Oh boy...to tell you the truth, um, I don’t worry not that much”

Another participant added:

“I don’t know, I mean I’m not really concerned about getting older because everybody’s gonna get old [laughs].”

On the contrary, one participant expressed personal concerns regarding getting older stating:

“Breakin’ some bones...I’m getting old too fast. Too fast...It’s like, when I was young, I used to think, oh these old people...now it’s like, I’m getting there! I just wish I could do everything I used to. I used to be so flexible when I was young. I’m not flexible anymore.”

Similarly, five out of the 13 participant reported not having any concerns regarding family members growing older.

One participant straightforwardly stated:

“They all do.”

Another participant expressed:

“Well yeah because I know they’ll be gone before me [*chuckles*] they’ll be gone before I’ll be gone.”

A third participant with living parents expressed concerns about them growing older stating:

“Ah, I worry about them more. A lot more because they’re getting way older than me. And I’m like [reference to dad] I’m afraid of him even trying, or trying to [climb ladders] by himself because when he was younger, he could, and now he’s older and it’s like, I have to hold the ladder and stuff for him.”

**Health and fitness.** When participants were questioned on how much exercise they got per week, interestingly, many of the participants reported getting the bulk of their exercise at work. Six out of the 13 participants felt that the exercise that they got during the workday was more than enough. Other participants reported going on occasional walks with staff members or while out shopping. One participant shared:

“Oh, I get plenty of exercise in that laundry [*laughs*]. That wears ya out.”

When asked the type of exercise they got, another participant responded:

“Walking. Almost every day at work.”

A third participant explained that exercise was situational for him, saying:

“Weekly basis. I would say, zero. If I’m out during the summertime, I get bucu. Since it’s starting to be like winter, I really don’t. I walk around the house. I try. When it’s raining like this and stuff its like, I don’t even try anymore.”

Finally, another participant described getting physical activity with their staff, stating:

“I just walked today. We [staff] walked today, me and her did.”

**Falls.** Out of the 13 participants, eight (62%) reported having falls or near falls in the past. Of those participants who reported falls, five stated that it happened in their homes. Other reasons participants reported falls included seizure-induced falls, lack of proper grab bars outside of the bathtub, falling out of the bed, slipping on ice, and impulsivity. One participant said:

“Yeah, when my foot slipped inside of a vent, I fell [*laughs*]...at my house”

Another participant described a fall in the bathroom stating:

“Yeah, oh yeah. In bathroom...Yeah, because I didn’t have the right kind of rugs”

A third participant discussed a seizure-induced fall, saying:

“I had a seizure one time at my place where I used to be at. I fell right over on my side and I couldn’t get back up. They had to rush me to the hospital and stuff.”

### **Socialization**

The importance of maintaining social relationships was recognized by all participants whether in-person or through social networking. Many participants without living relatives relied on socialization organized by Sunshine Inc. or local senior centers. One participant said:

“I got, not too many of my family’s around. They’re all gone...I got a lot of friends at [senior center].”

Additionally, two out of the 13 participants reported pets being a great source of companionship in the home. One participant stated:

“My dogs and my two cats are at home, and I got my friends [*laughs*].”

In response to any feelings of loneliness, another participant added:

“...No, my cats around.”

**Socialization in the workplace.** A noteworthy subtheme that ascended out of the topic of socialization included friends within the workplace. When discussing friends, five out of the 13 participants (38%) reported having and spending time with friends while at work. One participant shared:

“Well I have friends at work. We get together and I see them like once a week at bingo. That’s about it”.

Another participant stated,

“I have some at work I sometimes talk with.”

A third participant described her friendships stating:

“Well my friends, I got, a lot of my friends work here [Sunshine Inc. campus].”

**Social outings.** When participants were asked if they enjoy social outings, all 13 agreed that it was meaningful. All participants consistently identified the need for social interaction and outings with friends and staff as an important part of daily life. One participant said:

“Yeah, I enjoy, I like being around people”

A second participant added:

“I go out, like last night I went to the Olive Garden. They had like a men’s outing. Next week will be the ladies, then the week after will be the men...But I like to get out and see other people”.

Another participant excitedly described some of the week’s activities stating:

“Yeah, we’re supposed to go to a movie this week...Yeah, and we also do like the craft shows and everything.”

**Family involvement.** Other participants with living relatives discussed spending time with family members on weekends, or for parities. Moreover, holidays were particularly popular for gathering with family members. One participant said:

“...I see my family like once every few months. Like this Sunday, we’re doing some birthday parties for the baby kids”.

A second participant stated:

“...well every Saturday I do something with my sister...bowling.”

A third participant added:

“Well, sometimes it’s on a holidays.”

**Importance of staff.** When asked if participants had anyone to talk to when they felt lonely, many reported confiding in roommates (23%) and staff (38%). One of the 13 participants

referred to his old staff as family. This portrays just how important the roles of staff members are many of these participants. He stated:

“Oh yeah, I got, I got my old staff. She works at church. She’ll pick me up at 10 o’ clock. I had her almost 18 years.”

Another participant was asked who he was able to talk to about personal things and he replied:

“Some of the staff. Tell them.”

### **Employment**

Many of the participants found meaningful activity and enjoyment in their work life not only because of the socialization, but also for the occupation of working itself. In discussing work, one participant stated:

“It’s fun to do, gets me out of here for a while, I get to enjoy my friends...just hang out.”

Another participant added:

“...Oh, being around people, learning new things, and stuff like that.”

**Job satisfaction.** Only one of the 11 participants with jobs reported not being totally satisfied with his job. This provides significant indication of how meaningful the occupation of working can be to individuals with I/DD. When asked if there was anything participants did not like about their job, one participant said:

“No, I got too many friends on my bus, and co-workers.”

Another participant said:

“...I come in, do my job, the end...yeah it soon nine years.”

A participant with a mild criticism regarding the workplace responded:

“No. Oh! There’s one supervisor. She’s a headache supervisor I call her.”



**Retirement.** Though many of the participants had an idea of the age most people retire at, eight out of the 13 participants (62%) expressed little to no concerns regarding retirement.

Participants with jobs were asked what age they saw themselves retiring. One participant said:

“Well, that’s a good question, um, probably when...I don’t know, I’m 65 or so, somewhere in there...I just want to keep working ‘cause I love my job.”

Another participants stated:

“Well it all depends. I can retire when I turn 65, but it all depends on if my finances are right. But if not, I’ll just continue working ‘till the doctor says I can’t work no more.”

A third participant answered:

“Oh, one of these days I’ll give up, but I don’t know when that’s going to be.”

### **Overall Life Satisfaction**

The fourth theme was overall life satisfaction. Remarkably, most of the participants interviewed revealed little to no concern regarding the future in terms of successfully aging in place. One participant was asked what would make life easier right now or in the future and he stated:

“Basically, I probably won’t need anything.”

**Aging in place.** Most of the participants expressed overall satisfaction with their current lifestyles and living arrangements. When questioned about their overall satisfaction with their home environment eight out of the 13 participants (69%) reported being completely satisfied with their home settings. One participant said:

“I feel its God’s gift to me”

Another participant replied,

“I feel safe, I feel comfortable, nobody don’t break no windows or nothin’ like that.”

A third participant insisted there was nothing that needed to be adapted to her environment, stating:

“Nope, it’s just the way it is. I like it this way.”

**Barriers to successful aging.** Though most participants saw nothing wrong with their homes, a few were aware of potentially hazardous obstacles in and around their environment creating barriers to safe and independent living. Participants who were not completely satisfied with their homes were asked to provide suggestions for how it could be improved to make their life easier as they continue to grow older. One participant stated:

“I would like to bring my cupboards down a little bit so I can reach them. They’re up so high, I have to get a step-ladder to reach stuff.”

Another participant said:

“I’d like to change the steps down a little bit. The one like going to out porch is too high. Could be a little bit shorter, and the one in the front too, needs to be a little bit shorter.”

A third participant shared:

“Well, sometimes I need a railing to go to the basement, so I need it.”

Finally, one participant discussed how inadequate bathroom modifications were frightening to him, stating:

“...and that’s what scares me because we have a towel bar that’s not hooked all the way into the wall securely.”

**Meaningful activities.** Participants continuously reported positive overall satisfaction in their daily and weekly leisure-related activities. Weekly activities included bowling, bingo, arts and crafts, shopping, watching television, movies, dinner, and other Sunshine Inc. outings. One participant was asked what his favorite activity was and he replied:

“Oh! There’s one’s that I used to like! What do you call it? Uh, oh bowling!”

Another participant added:

“...just want to go to [senior center] and do some artwork and stuff there.”

A third participant stated:

“Just going out to eat and having fun with friends and everything, yeah.”

### **Discussion**

The purpose of this study was to examine issues related to successful aging in men and women with intellectual or developmental disabilities. All of the men and women involved openly accepted the opportunity to disclose their personal thoughts and perceptions on aging with I/DD. The following segment contains the findings of this research. In addition, the discussion concludes with the study’s implications for occupational therapy practice, limitations of the study, and future research recommendations.

To generalize, it was found that although these men and women faced a variety of unique challenges in various areas of daily living, they still reported being quite content and satisfied with their lives overall. In addition, most of the participants reported having relatively good health although they acknowledged having multiple health issues. As previously stated, the most common diagnoses found within participants in the current study included high blood pressure, diabetes, seizure disorder, visual disturbances, and high cholesterol. These results are consistent with previous studies exploring health and aging related issues in individuals with I/DD. In Salvatori’s (2004) study, adults with I/DD frequently talked about various health problems; however, most of them were not complaining of deteriorating health. Likewise, in a 2008 study by Buys et al. on aging adults with I/DD, researchers found that perceptions regarding health did not emerge as a major concern in participants with one or more health conditions. Moreover, this

study also supports previous findings of falls within this population. Sixty-two percent of participants in the current study reported falls with most being in or around their home environments. Grant et al. (2001) noted that falls are a frequent and reoccurring health issue in people with I/DD and are one of the most common causes of traumatic injury. In addition, other health disorders such as seizures are associated with fractures and other injuries as well.

This study revealed the importance for the need to continue to afford individuals with I/DD opportunities for active participation and socialization. Many participants in the current study identified their main sources of social interaction being in the workplace. This supports previous discoveries from Engquist et al. (2012) that many older adults with I/DD work simply because of the need for ongoing socialization and support. Outstandingly, not one of the 13 participants in the current study reported working for the primary motive of income. This also supports why older adults with I/DD may have a significantly dissimilar view of retirement than the general population. In addition to socialization in the workplace, all participants in the current study identified the importance of social outings. Participant described several examples of their favorite types of outings including, but not limited to: movies, dinner, bowling, sporting events, and shopping. This supports previous research that individuals with I/DD continuously identify the desire for more social outings (Salvatori et al., 2003). It should be mentioned that participants did not report many issues of mobility, as Sunshine Inc., established transportation for work and outings for participants. Subsequently, it was found that the majority of participants had experienced death of family members, particularly parents, as they aged. About half of the participants were able to visit with secondary family members on occasions such as birthdays and holidays, but more significantly, was the number of participants who heavily relied on paid staff for support and socialization. This supports the concept that paid support workers are highly

valued by individuals with I/DD and that it is vital that agencies and support staff continue providing opportunities for active participation and engagement with this population (Carrinus & Lunskey, 2003).

Results of the interviews also revealed the importance of work for individuals with I/DD as well as their lack of concern with retirement. Many participants in the current study have held comfortable, satisfying jobs for many years through Sunshine Inc., and did not contemplate future retirement plans. Most participants in the current study understood that people typically retire in their 60s, however, many mentioned that they wanted to continue to work forever or until the day they die. This indicates that there may be some confusion or displeasure against the idea of retirement. Judge et al. (2010) stated that there seems to be a sense that when an adult with I/DD retires, he or she has ceased to be a full member of the community and is now on the periphery. Retirement may appear to be an upsetting experience, as the friendships, activities, and opportunities that were previously available are no longer there. Continuing to provide programming for individuals following retirement is an important factor in maintaining quality of life and meaningful relationships.

On the whole, participants in the current study expressed a great deal of overall life satisfaction with their current circumstances. Moreover, there was very little apprehension regarding aging in terms of remaining in their home environment. In addition, participants continuously expressed the desire to continue engaging in meaningful and leisurely activities. Most participants reported loving their current homes and did not want to change anything about it, however, participants who expressed concerns regarding environmental barriers that were counterproductive to successfully aging in place mentioned items like outdoor stairs being too high, kitchen cabinets being too tall, the need for grab bars, the need for stair railings, and basic

home fixtures. However, participants seemed to be more enthusiastic about continuing to engage in meaningful occupations in life. This supports Salvatori, Tremblay, and Tryssenaar's (2003) findings that individuals with I/DD were more focused on more day-to-day "lived" experiences, including the need for more meaningful activity, more positive social relationships, and more personal autonomy.

As further research in the area develops, findings can be applied to the development and practice of more effective programming for successful aging in place for older adults with I/DD, especially for home evaluations and post-retirement occupations. All-in-all, participants in the current study were active in their communities and were very happy with their quality of life at this point in time as evidenced by their responses.

### **Implications for Occupational Therapy**

Literature supporting methods for successful aging in place in individuals with I/DD is exceedingly insufficient. With the day-to-day perspective that some individuals with I/DD have, it is important that occupational therapy practitioners, in conjunction with other service providers, help facilitate healthy, productive aging. The major themes presented in the current study can be addressed by occupational therapy practitioners in a variety of ways including health and wellness management, fall prevention, job training, post-retirement programming, and home and safety assessments and modification.

Occupational therapy practitioners have the unique skillset to view individuals in a holistic sense in their daily lives as well as cross the lifespan. With the increased prevalence of age-related health conditions within this population, occupational therapy practitioners can help promote healthier lifestyles by incorporating simple diet and nutritional regimens, exercise and physical activity habits, and address barriers between client's abilities and their daily lives. In

addition to maintaining optimal health, occupational therapy practitioners are knowledgeable in fall prevention strategies. With falls being one of the greatest factors in health decline in older adults with I/DD, occupational therapy practitioners are suited to evaluate and address a person and their environment to maximize safety and independence as well as assess the client's limitations contributing to falls. Interventions include home modification, increasing physical capabilities, changing behaviors and patterns of activity, and educating direct service providers as well as clients.

As supported by the literature, individuals with I/DD find significant meaning and value in continuing to work and staying active, even as they continue to age. Occupational therapy practitioners assess the demands of the workplace and evaluate the individual's abilities as well as obstacles to completion of work-related tasks. In addition to physical demands, they assess one's cognitive and behavioral demands in order to match individuals with I/DD with a successful job placement. Interventions include, but are not limited to, completing an evaluation of the demands of the client and workplace, establishing supports in the workplace, determine if adaptive equipment is necessary, determine accessibility and safety, and develop implementation programs for behaving in socially appropriate manner in various situation. On the contrary, individuals with I/DD continue to desire to be active and engage in meaningful occupations following retirement. Occupational therapists are able to help this population develop new skills inside and outside of the home and support community integration and participation. Interventions include, but are not limited to educating direct service providers on community integration and organizations in the community, educating direct service providers on ways to engage clients in daily home occupations and leisurely activities, and establish volunteer opportunities.

Participants in the current study identified the need for various home modifications to make daily occupations easier and safer for them; however, participants were unaware of how they could get their homes modified or who they could contact. Occupational therapy practitioners play an important role in identifying ways to enable environmental modifications in order to maximize the ability to participate in meaningful occupations. When considering adapting one's home environment in order to promote independence and safety, occupational therapists can complete an evaluation of client demands as well as a home assessment. Likewise, they identify environmental barriers that pose for increased risk for falls and injury and determine what modifications are required to promote maximum independence and safety.

### **Limitations**

Several limitations to the present study are highlighted. First, all recruited participants were affiliated with, and received services from Sunshine Inc. The experiences and perceptions between these participants and other community dwelling individuals with I/DD on the topic of successful aging may or may not significantly vary. For instance, in previous studies, transportation and mobility were a major concern of individuals with I/DD, however, Sunshine Inc. provided transportation services to recipients for work and social outings. Secondly, it is recognized that the perceptions and feedback of 13 older adults with I/DD cannot represent the total population of adults who are aging with I/DD. A larger sample size with greater geographical coverage could yield to more diverse participant responses on this issue. Likewise, participants were vastly male with only three being female. For this reason, results cannot equally represent the perceptions of both sexes.

Next, only verbal participants were chosen to participate in the current study. This fails to represent the perspectives of non-verbal individuals aging with I/DD on successful aging. In



addition, participants were all briefed on the purpose of the study and assured that their names would be kept confidential; however, it is possible that upon recruitment, study participants may have agreed to participate in this research study without completely understanding the intent of the research, confidentiality measures, and potential dissemination of results. With that being said, many of the questions required clarification and rewording for participants. This could have led to unintentional biased responses.

Finally, during some of the interviews a staff member was present, and sometimes an outside disturbance would occur, thus distracting participants from the dialogue. Therefore, having staff nearby had the potential to help or inhibit participant responses. Undoubtedly, staff proved to be helpful in clarifying communication challenges and providing specific information to some responses. However, the presence of staff may have decreased the opportunity for participants to answer questions first, potentially creating a bias answer. Also, some participants were distracted during the interview by noises or roommates which resulted in divergent or extraneous comments.

### **Future Research**

The findings in this study warrant further research specific to the aging-related needs and perceptions of older adults with I/DD. Primarily, recruiting a larger sample size of participants from a greater geographical region outside of Sunshine Inc. would yield to a more diverse pool of responses and perceptions. In addition, striving to acquire a more equivalent number of males and females may help to uncover interred data. Another area of development is to conduct a vigilant review of interview questions and wording. Additional research on suggested universal language may decrease biased responses and promote more accurate answers to requested inquiries. Also, incorporating an in-home assessment and the use of observation in and around

the living environment can give researchers clearer insight into the environmental barriers that many community-dwelling individuals with I/DD face daily, thus giving occupational therapy practitioners more accurate insight on the perceptions that this population is trying to convey.

### **Conclusion**

Overall, participants in the current study expressed a great deal of overall life satisfaction with their current circumstances. There was very little fear regarding future aging concerns and participant's current environments. In addition, participants continuously expressed the desire to continue engaging in meaningful and leisurely activities including work, outings, and individual hobbies. Additional research is needed to uncover the specific growing needs of this aging population in terms of what they feel they need to age successfully. As more research in this area develops, occupational therapists can apply findings to the development and practice of more effective programming and interventions for successful aging in place for older adults with I/DD. In the meantime, providing for opportunities for work, socialization, safety, post-retirement occupations, and meaningful activities are all important aspects that individuals with I/DD have voiced in maintaining enjoyment and quality of life.

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Appendix A  
Participant Questionnaire

**Participant #** \_\_\_\_\_

Diagnosis \_\_\_\_\_

Age \_\_\_\_\_

Gender: M F

How long have you lived here?

Who are you living with?

Is your mom or dad still alive?

How many siblings do you have?

## Appendix B

## Interview Guide

**Introduction outline**

- After arriving, participant will be greeted, checked-in and asked to fill out an informed consent agreement.
- Once an informed consent (if guardian has to sign, ascent form) is collected, participant will be asked to have a seat comfortably.
- Welcome:
  - Thank participant
  - Introduce the primary and secondary interviewer
  - “I am interested in learning about your perceptions on getting older what you feel that you need in order to age successfully”
- Overview of the study:
  - “You were chosen because we believe that you can provide valuable insight into the experience of growing older with a developmental disability.”
  - “The results will be used to meet requirements of my scholarly project for the completion of my occupational therapy doctorate degree from the University of Toledo.”
- Establishment of general guidelines and ground rules:
  - There are no right or wrong answers
  - This discussion will be recorded on this audio recorder so please speak loud and clearly as possible.
  - We are only going to use your first name to maintain confidentiality



- If at any time, you become uncomfortable, please feel free to stop and/or excuse yourself from the interview. There will not be any penalties if you chose to do so.
- If you have a cellular phone, could you please turn it off or silence it?
- Introduction Script (Kreuger 1994)
  - Good afternoon and welcome to our interview today. Thank you for taking the time out of your day to talk to use about aging with a developmental disability. My name is Nicole Johnson and I am an occupational therapy student at The University of Toledo. Assisting me today is my assistant moderator, Dr. Hatkevich. I am here for the purpose to guiding the interview, and the assistant moderator will be talking notes and asking questions if necessary.
  - Our purpose is to find out more about your personal perceptions on aging, and what you would like in order to age successfully here. We are interested in your experiences and opinions because we believe that you can help in educating people on providing assistance to aging adults with intellectual/developmental disabilities.
  - You were chosen to be a participant in this study because we believe you can provide valuable insight into the experience of growing older with a developmental disability and the challenges that you face. There is no right or wrong answers, just your own opinions. Please feel free to share any insight that you may have. The results of this study will be used to meet the requirements of my scholarly research project for the completion of my occupational therapy doctorate degree from The University of Toledo.

- Before we begin the interview, allow me to provide some ground rules. This is a research project. Please speak loudly and clearly as possible. We will be audio recording this interview because we do not want to miss any of your comments. We will refer to you by first name only, but later on we will not use your name. Maintaining your confidentiality is very important to us, and we will make sure to keep it private. We are interested in your good comments as well as your bad comments. If you have a cell phone, please turn it off or put it on silent.
  - This interview will last about 1 hour so let's begin.
- **Icebreaker: Just so I can get to know you a little better, tell me what a typical day is like for you.**
1. **Questions regarding health: What does getting older mean to you? What are your concerns about getting older? How about your family members getting older?**  
[RATIONALE: This is from Havercamp et al. (2004) study and it is going to help identify health concerns]
    - a. How would you explain your health overall?
    - b. How much exercise do you get on a weekly basis? Do you feel that it is enough?
    - c. Have you ever been to the dentist? Doctor?
    - d. Do you have any concerns about getting older
    - e. Have you ever fallen? (where were you?)
  2. **Questions regarding socialization: Tell me about your friends and family**  
[RATIONALE: This is from Salvatori et al. (2003) study and it is going to help identify socialization concerns]

- a. Do you enjoy social outings?
  - b. Do you feel that you have people to talk to about personal things?
  - c. Do you ever feel lonely?
- 3. Questions regarding mobility:** [RATIONALE: This is from McInerney and McInerney (1994) study and it is going to help identify mobility concerns]
- a. When you need to go somewhere other than Sunshine, do you have a way to get there
  - b. Do you know how to take public transportation? (Busses, taxis, etc.)
  - c. Is there anywhere that you would like to go that you can't? Why?
  - d. How often do you get to see family?
- 4. Questions regarding work:** [RATIONALE: This is from Engquist et al. (2012) study and it is going to help identify health work]
- a. Do you have a job? If not, would you like to have a job?
  - b. If answered yes to number 8, do you like your job? Why?
  - c. What do you like/dislike about your job? (If answered yes to number 8)
  - d. How long do you want to work? (If working)
- 5. Questions regarding home environment: Where do you live?** [RATIONALE: This is from Engquist et al. (2012) study and it is going to help identify home environment concerns]
- a. How do you like your house? Why/Why not?
  - b. Does your house have everything that you need?
  - c. Is there anything that you would change about your house to make things easier for you?

6. **Questions regarding overall needs: What do you want to keep doing in life? How often?** [RATIONALE: This is a part of the main question and we are trying to find out]
  - a. What are your favorite activities that you enjoy doing?
  - b. Is there anything that you need right now or in the future to make your life easier?
  - c. Is there anything that you wish others knew that could help you?
7. **Questions regarding occupational therapy:** [RATIONALE: This is a part of the main question and we are trying to find out]
  - a. Do you know what occupational therapy is or what an occupational therapist does?

#### **Occupational therapy information and resource**

- Before we conclude, do you have any questions or comments for us?

#### **Script for Closure:**

- Thank you very much for your time and participation, it was greatly appreciated.