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Family Opinions of Their Adult Children with Developmental Disabilities Aging Successfully

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Abstract

Little is known about the aging process of those with intellectual and developmental disabilities (I/DD). It is known that those with I/DD are living longer than in previous decades and in turn, require care for their specific and unique aging needs. The purpose of this study was to explore the needs of adults aging with I/DD as viewed by family members. This study sought to: 1) discover the role family caregivers' play in the lives of their adult loved ones with I/DD; 2) identify the major issues affecting successful aging of adults with I/DD; and 3) discover how family members feel occupational therapy can benefit their loved ones. Participants were self-selected and educated about the study through a variety of methods. The authors used a focus group method, hosting four focus groups with a total of ten participants, nine female and one male. Nine of the participants were parents of someone with I/DD receiving services from a community-based facility and one participant was a sibling. Following each focus group, the moderator transcribed audio recordings of the focus group. Three researchers independently analyzed the transcripts to identify significant quotations and assign themes. The themes consisted of assurance of care with a sub-theme of aging parents, caregiver support, relinquishing care, diminished communication, decreased occupational performance, and engagement in meaningful occupations. Occupational therapy can play a helpful role in the aging process of those with I/DD and also their aging family members. Implications for occupational therapy include increasing occupational performance and engagement in meaningful occupation for those aging with I/DD. Occupational therapy can address the parent's needs as well with caregiver education and safe patient handling seminars.

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Health issues of those with intellectual and developmental disabilities (I/DD) will differ in terms of prevalence, rate of progression, degree of severity, and most important to this study, age of onset. This study will begin by addressing the growing issue in regard to the aging population of those with I/DD and their underrepresented prevalence among the general population. Next, the study will discuss the mental, physical, and social health complications concerning the well-being of people aging with I/DD. The last section will reveal the difficult family issues and concerns that arise in a family unit with a family member diagnosed with I/DD. The current study will address how occupational therapy as a profession can significantly benefit the population with intellectual and developmental disabilities as they age, along with family members of this population who are aging. Due to very little research being conducted on this topic, the outcomes in the current study will help decrease unhealthy aging of those with I/DD. To better understand the importance of the gap of research that needs to be filled by the current study, past research will be reviewed.

Prevalence

According to the Developmental Disabilities Assistance and Bill of Rights Act, developmental disability is defined as a severe, chronic disability, which originated at birth or childhood, is expected to continue indefinitely, and substantially restricts the individuals functioning in several major life activities. Developmental disabilities (DDs) were being diagnosed in about 1 out of every 6 children in the U.S. during 2006-2008 (Boyle, Boulet, Schieve, Cohen, Blumberg, Yeargin-Allsopp, Visser, & Kogan, 2011). This data also specified that parent-reported DDs have increased 17.1% from 1997 to 2008, which equates to about 1.8 million more children with DD than the decade before (Boyle et al., 2011).

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With the increase of people with DD being diagnosed, it goes without saying that the prevalence of adults with developmental disabilities will begin to rise. One of the most frequently used statistic about adults with developmental disabilities is the estimated prevalence of 4.6 million (Morstad, 2012). This statistic however, is from the 1994 and 1995 National Health Interview Survey and it is out of date and uninformed of recent changes in definitions and criteria of developmental disabilities. There are many difficulties in regard to collecting and analyzing data on what a disability is and who is diagnosed that includes; time, inconsistency, and changes in disability groups (Morstad, 2012). The discussed difficulties give more importance to the current study and its ability to add to the inconsistent base research on this topic.

Although there is little research to suggest the near exact amount of adults living in the U.S. with I/DD, a mix of reliable sources seem to agree that this population makes up about 1.5-2.5% of the general population. Given recent US Census data, it is approximated that the percentage previously stated translates to about roughly 4.6 million to 7.7 million people with I/DD (Morstad, 2012). As previously stated, demographic information on this population is scarce, but there is an estimated population of 850,600 individuals over the age of 60 living with I/DD (Factor, Heller, & Janicki, 2012). With the numbers continually rising, more research needs to be conducted on this aging population or the chance of adults with I/DD not living to their fullest and healthiest potential will increase significantly. Much like the general older aging population, issues and complications will come with the aging process. Many complications of being diagnosed with I/DD will play a role in aging successfully. More specific complications are detailed in the next section.

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Complications of Aging with I/DD

A study by Sullivan, Berg, Bradley, Cheetham, Denton, Heng and McMillan (2011) researched PubMed and PsycINFO for publications from 1990 to 2010 tried to identify the most prevalent health issues in the I/DD population. The authors concluded that general issues in primary care of adults with I/ DD could be a wide array of health complications not limited to any specific category. The prevalent health issues included dental disease, cardiac disorders, respiratory disorders, musculoskeletal disorders, and epilepsy. This is not an exhaustive list and only names a sample. Many people included in this population also take multiple or long-term medications and with this comes harmful side effects that can lead to pain and discomfort as they age. Frailty is a state of increased vulnerability to adverse health outcomes compared to others of the same age. A study by Schoufour, Mitnitski, Rockwood, Hilgenkamp, Evenhuis, and Echteld (2014) validated that people with intellectual disabilities (ID) are more frequently considered to be frail compared to the general population. The study also verified that individuals with I/DD are considered frail at an earlier age. The lack of ability to communicate is often an area that complicates daily living in those who have I/DD. Individuals with I/DD may not be able to verbally or physically express symptoms or how they are feeling at any given time making pain and distress often unrecognizable in this population (Braddock, 1999). Being unable to communicate the need for help while in pain is a frustrating and often unbearable way for a person to live.

Obesity due to poor nutrition and lack of activity can also affect this aging population (Sullivan et al., 2011). Vision and hearing difficulties can arise with aging but are under diagnosed in this population due to poor communication or ill educated caregivers. Activities of daily living can be difficult for these adults creating issues such as, gastrointestinal and feeding

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issues, sexuality struggles, and infectious diseases due to poor hygiene (Sullivan et al., 2011). Evidence also suggests that people with I/DD experience earlier age-related health conditions including incontinence, swallowing difficulties, sensory losses, adaptive behavior losses, and cognitive decline (Marks, Sisirak, & Hsieh, 2008).

Mood disorders and emotional distress are limited research areas with this population but there have been studies that show mood disorders are common in adults with I/DD. Misdiagnosis and under recognition of mood disorders and/or emotional distress continue to be a problem in community settings (Antonacci & Attiah, 2008). With this population, dementia is a common diagnosis during the aging process. Virtually all adults with Down syndrome between 35–40 years of age who were autopsied exhibited key neuropathological changes characteristic of Alzheimer's disease. These changes included deposition of beta-amyloid in diffuse and neuritic plaques and neurofibrillary tangles (Mann, Yates, and Marcyniuk, 1984). Health issues will vary from case to case but more research needs to be done to address the specific population of aging adults with I/DD.

Family Issues

Among family caregivers of adults with developmental disabilities, 25% of them are over the age of 60 (Heller & Factor, 2008). As a caregiver or family member, seeing health complications such as chronic disease, decreased mobility, and mood disorders in an adult child or loved one can be devastating. As a child, the issues discussed above are commonly taken care of by the child's parent, but as the child ages so will the parental caregiver. Because there is a growing life expectancy of those with I/DD, parents will be expected to care longer for their aging child.

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Caring for an aging child with a developmental disability can be financially, physically and emotionally difficult on an aging parent. There is very little research to suggest protocols on how to educate and help families of those with intellectual and developmental disabilities who are aging. Providing a plan of care for the time when the family caregivers may not be able to care for their child or loved one can also raise anxiety. No parent wants to think about a time when he or she cannot take care of his or her child. Financial and legal planning, future living arrangements, and vocational and recreational support are just a few topics that will have to be addressed in planning ahead. As parents age, siblings are often taking a larger role in care but are often unprepared (Heller & Factor, 2008). This will put a higher demand on health care providers in facilities and many different professions, including occupational therapy because they are often sought after for their professional opinions as well as often work closely to those with this diagnosis.

Occupational Therapy and I/DD

Occupational therapy is one of the many professions that will become beneficial to adults with I/DD and their families. Parents have reported a lack of knowledge about assistive devices and technology for their aging children with I/DD (Barnhart, 2001). Occupational therapists have the education on assistive technology that could help aging parents and children. As previously stated, activities of daily living are becoming a deficit in successful aging in those who have I/DD and it is in an occupational therapists' scope of practice to be able to provide services to help with this issue.

The American Occupational Therapy Association Standards of Practice for the Developmentally Disabled cited several reasons for referral to occupational therapy. These reasons include dysfunction in self-care activities, home-school-work activities, neuromuscular

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development, psychological development, sensory integrative development, social development, and cognitive development all were reasons for referral (Warren, 1986). These reasons clearly indicate that occupational therapists will play a major role in aging adults with I/DD. Educating the family is also a key role for occupational therapists, whether it is in home health settings, community based programs, or long term care facilities. Maintaining as much independence as possible can increase the quality of life for those with I/DD and diminish the burden for individuals, family, caregivers, and health care facilities (Andersen et al., 2004). Occupational therapists can be available in a variety of settings, which makes them perfect for the specialized treatment needed for individuals with I/DD to age successfully.

The Current Study

Ideal health involves biological, social, and mental factors interacting effectively. It is important to incorporate caregivers and family members' opinion in the research process to better understand what aging factors are affecting individuals with I/DD. If these factors are not addressed, it is possible for health disparities to arise for those individuals with I/DD who are aging. Healthcare providers and family caregivers should have superlative and up to date knowledge to be able to help care for individuals with I/DD who are aging and who may have multiple diagnoses. Yet there has been limited facts identified in the literature about the aging process of those with I/DD.

Family is an important part of this study because family is a key factor in aging and aging with I/DD successfully. Researchers need family opinions of their loved ones aging to fully understand how they are being taken care of throughout their life. This information will provide the knowledge to make improvements in care to benefit those aging with I/DD. Family members can shine a light into emotions and frustrations that individuals with I/DD may not be able to

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express themselves. Family members may give loved ones a voice to express their changing needs and wants as they age. Also the more family opinions that researchers discover, the more information and advice families can have to help their family members with I/DD age successfully.

The current study attempts to improve quality of life, increase knowledge, and prevent suffering, morbidity, and premature or unnecessary death in adults diagnosed with I/DD during the process of aging. The right to live one's life to its fullest capacity is a right that should not be denied to anybody. The current and future studies are necessary to give the right of aging successfully to adults with intellectual and developmental disabilities and the ability to live life to their fullest capacity and highest quality.

This study specifically looked at family opinions of successful aging of their loved ones with I/DD. The research questions for this current study were:

- What roles do family caregivers play in the lives of their adult loved ones with I/DD?
- What are the major issues affecting successful aging of adult children with I/DD according to family caregivers?
- How can occupational therapy help in successful aging of adults with I/DD and their aging family members?

Methods

Participants

Participants in this study all met the following inclusion criteria: (a) be 18 years old or older, and (b) be a parent or sibling of a resident of Sunshine Communities Inc. Sunshine Communities Inc. is a non-profit organization that provides services to individuals with developmental disabilities across northwest Ohio. The services provided include residential,

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vocational, family support, respite, recreation, and clinical services. Demographic information on participants was collected on each participant (see Appendix E for demographic questionnaire) A total of four focus groups were performed with a total of 10 participants. The first focus group included three participants. The second focus group included two participants. The third focus group included three participants. The final focus group included two participants. The age of participants ranged from 50 to 76 years old ($M = 67.5$, $SD = 8.42$). The age of participant's family members with I/DD ranged from 23 to 55 years old ($M = 44.6$, $SD = 9.66$). The specific diagnosis of each of the participants' loved ones varied but all fell under the umbrella of intellectually and developmentally disabled. Nine of the ten participants were parents of individuals with I/DD and one participant was a sibling. In regard to marital status, six participants were married, two were widowed, and two were divorced. The highest education level was a master's degree. All of the remaining participants had at least a high school education.

Sampling Procedures

This study was conducted at Sunshine Communities Inc. Participants were recruited through flyers and through e-mail (see Appendix B and C for recruitment flyer and recruitment e-mail). The recruitment period began in the winter of 2013 and lasted through the spring of 2014. No monetary compensation was provided to the participants of this study. The Institutional Review Board (IRB) at The University of Toledo approved all procedures of this study.

Measures

Focus groups were used in the study for many reasons: they allowed for a larger sample size, they were easily conducted, they were economically efficient, and collection of data was done quickly and most conveniently (Krueger, 1994). The focus groups lasted approximately 90

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minutes each. Due to a lack of current research on the topic of aging adults with I/DD, these focus groups relied on discussion and group interaction to help identify concerns for aging, common opinions, and similar experiences. Researchers used probing questions to guide the family members to discuss their opinions about how their loved ones are aging and what they believe could help them age more successfully (see Appendix D for the focus group protocol).

As participants entered the research area, they were greeted by the moderator and asked to fill out a consent form (see Appendix E for consent form). The participants were also asked to fill out the demographic questionnaire. The participants were encouraged to ask questions regarding the consent form and questionnaire. Participants were also offered light refreshments. Morgan and Krueger (1997) wrote that refreshments can be seen as an incentive and create an inviting atmosphere. The moderator then reminded the participants that their participation would remain confidential.

Each focus group lasted approximately 90 minutes. Upon completion of each group, a summary of major discussion topics and opinions were reiterated to the group to ensure that the moderator did a proper assessment of topics. Two audio recording devices were used to record the focus groups. Two devices were used in the case that one of the devices failed or malfunctioned. Directly after the completion of each focus group, the researcher and research assistant checked the recordings of the group to make sure the audio was captured and could be replayed. This helped maintain the integrity of data collected during the study (Krueger, 1994). Tapes were then labeled and stored safely by the researcher and assistant. The researcher and assistant also set aside time to discuss and document main topics of the group as well as ideas that could be beneficial for the next focus group.

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Data Analysis

The following data analysis was used to create reliability and validity for the current study. There were three student researchers and two research advisors overseeing data analysis to enhance the study's credibility. Two students and one research advisor did the thematic analysis. Krueger created an outline with the following steps to analyze data properly (1994):

- a.) The moderator used audio recordings and field notes to produce a transcript belonging to each focus group. Each of the three researchers read the transcripts to note significant or important quotes from the participants.
- b.) After each of the three researchers independently reviewed the transcripts, the researchers met via conference call to discuss and identify significant participant quotations. From this discussion, a major list of quotations was formed for further review.
- c.) The three researchers independently reviewed the list of quotations to select and identify themes and categories. The researchers met again via conference call and created a coding scheme for major topics.
- d.) The three researchers independently reanalyzed the quotations in terms of the coding scheme to further identify and analyze key themes.
- e.) The three researchers met again via conference call to compare their individual findings. Categories that were unused were terminated and categories that overlapped were combined. Researchers developed a final coding scheme and reanalyzed and recoded the data using the final coding scheme.

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Results

Six major themes and one sub theme was identified by the three researchers based on the analysis of the four focus group. The themes were comprised of assurance of care with a sub-theme of aging parents, caregiver support, relinquishing care, diminished communication, decreased occupational performance, and engagement in meaningful occupations. Each individual theme will be discussed in further detail during the remainder of this section and specific participant quotes that correlate to the theme will be discussed. Additionally, some information has been added to clarify the responses and are included in brackets [text], while the omission of trivial words and/or phrases have been designated by the use of ellipses (...). Names have also been removed to protect the individual's privacy.

Assurance of Care

During the focus groups it was apparent that there was general "worry" from the family members about what kind of care their loved ones with intellectual and developmental disabilities would receive when they were no longer able to care for them. A concern of the aging parents seemed to be who would take care of their children and would the care be as good as a parent's care. Some participants had multiple children that they didn't want to "burden" with the care of their child with I/DD and others would be reliant on community-based facilities once they aged and were no longer able to care for their child. For instance, one participant described her worries:

"I also know that if she is aging, I am aging. And who is gonna be there for her when my husband and I are not. She does have siblings but it's kind of complicated and different. The sibling relationship is different. I

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have boys that live out of state and they would look after her but probably not to the same degree that I would.”

This parent discussed the difficulty caring for his/her child as time goes on:

“Not because he is getting older but because I am getting older, I have had to step back from doing things. I used to do more for him but it’s gotten to the point where I have had to have injections and therapy and they tell not to do things anymore. Now I am asking them (staff) to do more and me do less but that’s not going too well. That’s the problem, we are getting older.”

Aging Parents: This sub-theme under assurance of care was significant in this study because the parents were concerned about the level of care their loved one would receive due to their aging. The fear came from the possibility of being unable to physically care for their loved one and having to relinquish care to someone else. As the parents aged, they came across limitations that prevented them from caring for their child with I/DD. A parent talked about why it was important to be proactive about looking for support and help from community-based facilities:

“Yeah, it’s hard to physically keep up. That’s why it’s important to think about it early and not when you start to have issues.”

This parent discussed how a short visit from his son to their home has changed as he and his wife have aged:

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“Now at this stage he wears us out. After having him home for a few hours we are ready to take him back because I could not handle him all day. He doesn’t slow down. He is always going. He is just so active, he would wear me right out.”

Caregiver Support

Community resources, transportation, and services provided by facilities, were a few of the common topics under the theme of caregiver support. Most family members stated they felt they needed more support from the community; financially, emotionally, physically, and in terms of services such as respite care. This participant explained what respite care was to her:

“I just wish there was more help if I needed it. The respite time is what really helps me, you know. It’s just like a little break that I need to be able to keep my sanity most times.”

Another participant was asked what she felt she needed to help her loved one age more successfully and she answered:

“A more accessible home, like I was just saying we have a hard time getting her home as it is and a home without stairs would work better. Or if I had someone I knew who could help me. Whether that’s a professional person or what. Just to go to the store I would have to hire someone.”

This parent discussed the organization and financial aspects of finding help to keep her son at home with her;

“Because if they want our kids to stay with us in our house they need to give us more, give us more help. You know and you’ve got the huge bureaucracy that you’re working with that have hundreds of people

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working and if you just don't use so many people maybe you could spend that money on help for us or something. It always comes down to money.”

Relinquishing Care

This theme was discussed a great deal in terms of transition of care from home to a facility or group home. Participants felt it was hard to give up control of their loved ones care while others had an optimistic attitude towards a more independent lifestyle for their loved ones. There was also a good discussion about the process of relinquishing care to facilities including “wait lists” and when is the “right time” for your loved one to leave home. This participant described the struggle of caring for multiple children, older parents, and the choice she needed to make regarding help from a facility:

“We were to the point where I couldn't find anybody to watch her, you know qualified to watch her. We would take turns doing things, you go here I'll watch her, now you go there and I'll watch her and I had two younger kids too and then I was always having two older parents that I needed to help at two different facilities so you know it got, it came at the right time. That change was a relief; it was at the right time. I mean it was hard, it was difficult and I felt a little guilty but happy at the same time. It was a change. I was able to give a little more attention to the younger kids cause I didn't have to watch her.”

This parent discussed the options that have to be weighed as she made choices regarding having to relinquish care of her child due to aging:

“But I also know that if she is aging, I am aging. And who is gonna be there for her when my husband and I are not. She does have sibling but

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it's kind of complicated and different. The sibling relationship is different.

I have boys that live out of state and they would look after her but probably not to the same degree that I would.”

Another participant talked about the emotional toll it took to relinquish care of her loved one:

“I feel so responsible, it's hard to step back to let the staff take care of her.

It's bittersweet to see her bond with staff because deep down, not even deep down but on the surface, I wish it was me.”

Diminished Communication

Communication is a very important part of life for everybody. When there is a deficit in a person's ability to communicate, needs, wants, and desires may not be able to get expressed.

Diminished communication was a common frustration among those with I/DD and their family members. A participant explained the difficulty in caring for someone who cannot always communicate wishes:

“I don't think he feels real well, his legs swell but he doesn't tell you when he feels bad he is just grouchy. He can't say “I have a headache” he never could tell me what was wrong. He would say his cheek hurt so we had to guess was it his tooth, his mouth, his ear? He never could explain.”

This parent discussed how her loved one's lack of ability to communicate can turn into physical behaviors:

“She can get violent sometimes when she can't express herself or isn't getting her way you know? To work her out of that since she can't talk she can't express where as you or I would call a friend and be like “blah blah

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blah blah blah” she can’t do that you know. She can’t express herself that way so she takes it out a more physical way”.

Another participant discussed the transition from care at home to care at a facility and being unable to know what it put her daughter through:

“[...]It’s hard to know because of her lack of communication. The biggest thing for her and for me was adjusting to living here [in a facility] after being home for 19 years so I don’t really know what she went through.”

Decreased Occupational Performance

During the focus groups, the loved ones noted that as their family members with I/DD aged, they noticed a decrease in occupational performance or occupations of daily living. Some felt it was due to increased physical limitations and others felt it was due to motivation or emotional changes. Here one participant talked about how she believed the schedule of group home care and her loved ones physical decline impacted his occupational performance:

“He lives in a group home and pretty much everything is done for him. He can still do a lot of things, he can still dress himself kind of and he could do it. So they just dress him cause it takes forever for him to do it so it’s easier for the group home to do it cause they are on a time schedule.”

This loved one discussed a physical and mental decline she noticed with age that she attributed to decreased occupational performance:

“She moves slower. Several injuries, she fell and broke her ankle. That set her back. She was in OT and PT for that for a fair number of months. I have seen a lot of what you could call dementia but the family doctor

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continues to tell me she has the body of an 80 year old even though she is in her mid-50s.”

This participant talked about a decreased energy level she has seen in her loved one as she ages:

“She was extremely active, they used to call her wild woman cause she was all over the place and full of energy. But she doesn’t seem to have that like she did in the past.”

Another participant discussed the increased self-esteem that occupational performance brought her loved one:

“(name redacted) loved to be independent and if they just had the time and the staff he could do more for himself and he would feel really good about himself. It really makes a difference.”

Engagement in Meaningful Occupation

When asked what they wished for their loved ones as they age, participants mentioned they would like their loved ones to stay involved and participate in meaningful activities/occupations to the best of his or her ability. This was a priority in terms of level of care that all the family members agreed upon. One participant talked about what she hoped the future for her loved one would look like and what it would not look like:

“As they age I also don’t wanna see them sitting in a corner in a chair just rocking or something, I want him to have meaningful things to do.”

This parent discussed the importance of occupational performance and independence for her loved one with I/DD:

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“For (name redacted) the vision for him and myself would be for him to be more productive. Do things he wants to do things for you. If you drop something he wants to go pick it up. He wants to be part of his environment, not just someone in a wheelchair waiting for people to hand him things. And he can do things if they would let him.”

Another parent discussed the importance of leisure as an occupational performance as well as the importance of outings for her loved one:

“I want her to be content and do the things she enjoys so when I say a lady of leisure, I want her to be able to go out and get her hair done and equestrian therapy. She loves the water so I want her to be able to not only use the pool here but go out as well. I always feel negative when I say this but they bring everything to them. They bring the dentist here, they bring people to cut their hair. I want her to go out. That’s an outing.”

This participant discussed the importance of vocational services as well as the emphasis of independence during upbringing in her loved one’s life:

“And she washes tables and she is employed beyond her developmental level. Really she does a lot. And I don’t mean this to be braggadocios at all but we all pushed her, nobody made excuses for her. It was always, “come on” you can do that.”

Some important information was gathered during the four focus groups during this research study. The atmosphere and group discussion was not only ideal for gathering the information but also it created bonds between family members. It was also a release for

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caregivers to discuss their opinions and emotions with professionals and other caregivers that may be going through similar situations.

Discussion

The aim of this study was to identify family member's opinions of their aging loved ones with I/DD and their opinions on aging successfully. It was determined that most participants had very similar opinions, worries, and ideas. Analysis of the four focus groups resulted in the identification of the following themes: assurance of care with a subtheme of aging parents, caregiver support, relinquishing care, diminished communication, engagement in meaningful occupation, and decreased occupational performance.

Discussed first will be the theme of assurance of care with a subtheme of aging parents. A large focus was placed on the parents' aging affecting their children significantly. Among family caregivers of adults with developmental disabilities, 25% of them are over the age of 60 (Heller & Factor, 2008). The participants of this study were slightly older based with an average age of 67.5. Caregiver issues with caring for their loved ones as they aged included fatigue, decreased strength, and diminished endurance. This is consistent with Heller and Factor (2008) who provided reasons for an increase in care from the outside. The reasons included, but were not limited to, aging parents with decreased physical ability and fatigue. Due to parents aging, siblings are taking a larger role in care but are often unprepared (Heller & Factor, 2008). Some parents stated they did not want to "burden" their other children with caring for their child with I/DD and other parents stated they did not believe that their children would give the same level of care as the parent's themselves would.

For those with loved ones in a group home or facility, they expressed worry about how the staff care would be different from their own and how staff turnover would affect his or her

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loved one's aging process. Hewitt and Larson (2007) stated paid staff recruitment and retention was among the most significant barriers to providing quality services for individuals with I/DD. The participants noticed a high turnover of staff providing care for their loved ones and stated that it had a negative impact on their loved ones with I/DD.

Caregiver support was another prominent theme throughout the four focus groups. Examples of support that the individuals wanted were respite care, financial support, and assistance with the means to keep their child in the home. One participant noted that respite care was the "break" she needed and linking her with community facilities that offer respite care would be beneficial in order for her to care for her loved one successfully.

Another participant stated that her home was not ideally accessible to accommodate her loved one with I/DD. Home modification is one way of helping this population age in place because it can improve safety and even slow functional declines associated with aging and disability (Mann, Ottenbacher, Fraas, Tomita, & Granger, 1999). Stark, Somerville, and Morris (2010) determined the effectiveness of an assessment tool that could help identify home modification needs. The In-Home Occupational Performance Evaluation (I-HOPE) measures occupational performance, ability to perform, satisfaction with performance, and magnitude of environmental barriers' influence on performance. The I-HOPE can identify areas where environmental supports can be used to compensate for clients' functional losses (Stark, Somerville, & Morris, 2010). These tools could provide the support family members are looking for to help their loved ones age more successfully. They can also improve how successful the aging process occurs under the parents care, resolving worries from the parents such as assurance of care and relinquishing care.

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Another theme discussed was the involvement in meaningful occupation and its importance to aging successfully. Meaningful occupations are the day-to-day occurrences that bring specific meaning and quality to our lives. Family members often stated they wanted their loved ones to have choices and engage in activities/occupations that made them happy. Participation in these meaningful occupations, especially activities of daily living, also have a direct link to how much care their aging family member will have to give. Individuals need to engage in meaningful occupations because this engagement influences development, health, and wellbeing throughout the lifespan (American Occupational Therapy Association, 2011). If a person has a decrease in occupational performance, it could be said that that health and wellbeing also suffer. Diminished occupational performance can be accompanied by decreased self-esteem, increased anxiety or depression, and lowered independence. It could be summarized that aging successfully was defined by family members in terms of the amount of involvement in meaningful occupations along with an appropriate amount of independence in occupational performance.

To further expand on the topic of family opinions of their aging adult family members with IDD, a discussion of the implications for occupational therapy will highlight the second purpose of the current study; which sought to identify the role of the occupational therapist in this topic. Additionally, the limitations of this study will be discussed, as well as suggestions for future research.

Implications for Occupational Therapy

Some participants stated that their loved ones had received occupational therapy services or were currently receiving occupational therapy services. The services ranged from fine motor control and hand writing to aquatic therapy. Every participant that affirmed their loved one

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received occupational therapy indicated that they felt it was a beneficial service. One common opinion was that the family members wished occupational therapy services was more frequent and available to everyone at the facility, not just those with a referral.

Occupational therapy can play a role in the aging of not only those with I/DD but also with their aging family members. Caregiver support can be addressed by occupational therapists providing seminars on topics such as safe patient handling and caregiver burnout, as well as providing community resources and support groups. Educational training sessions on safe patient handling can help caregivers reduce the risk of injury while assisting his or her aging loved one who may demonstrate decreased functional mobility. Support groups run by occupational therapists would be beneficial to caregivers to help reduce burnout and provide professional advice on situations they may be dealing with such as, providing education on positive coping skills to deal with stress or demonstrating relaxation techniques. Occupational therapists can also provide caregiver support by completing home evaluations and suggest home modifications. An additional program that would be beneficial is a mentorship program offered in the same geographical area for family members caring for aging loved ones with I/DD. During the focus groups many family members had advice for each other that only a family caregiver could give. An example included how to take a step back from the caregiver role and remember they also are a mother or father. An occupational therapist could facilitate this mentorship program/group and add advantageous healthcare views.

To address the engagement in meaningful occupation, educating staff about the importance of meaningful occupations for those with I/DD would be important to increase their quality of life as well as putting family member's minds at ease. The therapist can provide creative ideas of ways to make the environment more meaningful to those with I/DD. An

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occupational therapist can offer a unique perspective of why meaningful occupations should be included in daily care. Some participants said that although their loved ones could perform their occupations of daily living, it was easier for staff to do it. Another participant stated that when her loved one was able to be more independent in daily activities it made a positive change in her attitude and mood. Maintaining as much occupational performance as possible can increase the quality of life for those with I/DD and diminish the burden for individuals, family, caregivers, and health care facilities (Andersen et al., 2004).

As previously stated, occupational therapy can be beneficial for aging caregivers as well as individuals with I/DD who are aging. From the findings of this study it is hopeful that occupational therapists will know more about how to help those aging with I/DD and their family members. The author believes this is a significant area where occupational therapists are needed..

Limitations

The current study implemented four focus groups with family members of individuals aging with I/DD. The study gathered the family member's opinions on their loved ones aging process and addressed how occupational therapy could help them age successfully. The researchers gained new and important data during the group's discussion but there were some limitations to the study.

The small sample size was limiting to the ability to generalize to every family member of those with I/DD. Also, participants were vastly female and parents which also affect the ability to generalize the results. Participant recruitment was limited to family members of those receiving services from one facility in northwest Ohio. Since the participants were pooled from a

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facility that cares for their family member, they may have been reluctant to speak unkind of the facility.

The focus group method of collecting data also had limitations to the study. It has to be taken into consideration that the moderator is responsible for prompting discussion about meaningful topics. There is a risk of the mediator intentionally or unintentionally influencing the discussion through personal bias. It is also possible biased opinions were gathered since the participants were educated on what type of study they were involved in. Participants may have varying agendas or reasons why they self-selected themselves to participate. During discussions, participants disagreed on opinions sometimes and were reluctant to voice major disagreements. Also, some participants knew each other's loved ones, which made participants hesitant to share negative things about their loved ones or specific details related to health or behavior. Language was a small limitation of the study due to English being a second language to one participant. This made it difficult to understand all of her opinions during transcription of the focus group records.

Future Research

Future research will prove to be highly beneficial to serving individuals with intellectual and developmental disabilities in their ability to age successfully. Future recruitment methods may result in a larger pool of subjects, therefore increasing the ability to generalize the findings. These should include methods to recruit both male and female participants, and recruitment should take place at multiple facilities throughout a larger geographic area in order to generate results that can be generalized to a larger population. The researchers would also like to see specific family member studied, for example, having a parent only or sibling only participant inclusion could help specify future studies. One area of need, according to the current study,

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would be future research on the specific physical and emotional tolls on parents caring those with I/DD as they age. This study was a qualitative study looking for the loved ones opinions but the researchers would like to see a quantitative study focusing on injuries, mental illness, and lifespan. Another area that needs continued research is the effect of caring for a loved one with I/DD on family relationships such as marriage. Some discussion was noted but not significant to include in this study about the impact of family dynamics on caring for a loved one with I/DD.

Conclusion

The population of aging adults with I/DD is rising at a rapid pace. This population faces age-related declines much earlier than the general population of aging adults, and due to issues addressed by this study, some needs remain unmet. Family members are aging alongside of their loved ones, creating new dynamics in care. Parents now have more decisions to make regarding their children's care and their own aging plays a key role in making these decisions. Occupational therapists are ideal to help with any situation including, continuation of safe in house care, transition of care to a facility, or continued facility only care. Occupational therapists are trained to encompass the care of the client aging with I/DD and also train the aging parent or caregiver on how to stay safe while caring for their loved one. The importance of meaningful occupations was stressed during this study and it is the perfect place for occupational therapists to share their skills with this population.

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Appendix A

Demographic Questionnaire

To help researchers be able to accurately describe participants in this study, please fill out the following survey. All surveys are anonymous.

- 1.) What is your age? _____

- 2.) What is your gender? Male Female

- 3.) What is the highest level of education completed? _____

- 4.) What is the age of your family member receiving services from Sunshine Inc.? _____

- 5.) What is your family member's diagnosis? _____

- 6.) Describe your relationship with this family member
 ___ Mother
 ___ Father
 ___ Step-mother
 ___ Step-father
 ___ Sister
 ___ Brother
 ___ Step-sister
 ___ Step-brother

- 7.) What is your marital status?
 ___ Married
 ___ Single
 ___ Divorced
 ___ Widowed
 ___ Other _____

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8.) Please mark the services your family member is receiving at Sunshine Inc. (may be more than one)

Residential Services (family care homes, supported living, family living program etc.)

Family Support Services (assistive devices, home modifications etc.)

Respite Programs (short term care from Sunshine Inc.)

Community Recreation (weekend recreation, after school/work recreation, small group recreation outings in the community)

Vocational Services (Georgette's, supported employment, book clubs, computer labs, etc.)

Clinical Services (warm water pool, sensory room, etc.)

Spiritual services (worship, etc)

9.) How many hours are you in contact with your family member per week? (via phone, visiting, etc.) _____

10.) Describe your involvement in your family member's care.

THANK YOU

Appendix B

Recruitment Flyer

Research opportunity for
family members of residents
at Sunshine Inc.

If you are interested in
participating in this study:

Please contact:

Hannah Robinson at

To **qualify** for this study you
must be:

- Over 18 years of age
- Parents or siblings of residents of Sunshine Inc.
(Only 1 representative per family please)

The purpose of the research is to learn more about:

- What role family caregivers play in the lives of their adult loved ones with I/DD?
- What are the major issues affecting successful aging of adults with I/DD according to family caregivers?
- How can occupational therapy help in successful aging of adults with I/DD?

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Appendix C

Sample Recruitment E-mail

Dear Parent or Sibling of Sunshine Resident,

My name is Hannah Robinson and I am currently conducting research at Sunshine in for the occupational therapy doctorate program at The University of Toledo. I am e-mailing to ask for you help in my research because I am researching family opinions of their how their loved ones are aging with intellectual and developmental disabilities. Focus groups will be conducted on Sunshine campus for approximately 90 minutes. If you have any questions or are interested in participating please e-mail me at this address or call at (330)-321-2799.

Sincerely,
Hannah Robinson
Hannah.Robinson@utoledo.edu
Occupational Therapy Doctorate Program
The University of Toledo

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Appendix D

Focus Group Protocol

Introduction Outline

- Researchers will first greet participants during arrival. Participants will be asked to complete informed consent agreement and fill out a name tag with his/her first name only.
- Once consent is established, the demographic questionnaire will be filled out by the participant and any questions regarding the consent and questions for researcher will be encouraged.
- Light refreshments will be offered and an opportunity for casual conversation will be given as more participants arrive to the discussion.
- Once everyone has arrived, the researchers will request that all participants be seated.

Script

Hello everyone and welcome. Thank you for giving us your valuable time to help us in our research of successful aging of those with intellectual and developmental disabilities. I am Hannah Robinson and I am currently in my second year of the occupational therapy doctorate program at The University of Toledo. I will be leading this focus group and a research assistant is taking notes about our discussion and your important opinions.

First, let me describe occupational therapy. Occupational therapy addresses the parts of your day that you find meaning or purpose in. OTs work in a variety of settings with many populations. The American Occupational Association states that common occupational therapy interventions include helping children with disabilities to participate fully in school and social

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situations, helping people recovering from injury to regain skills, and providing supports for older adults experiencing physical and cognitive changes.

Research has shown that more needs to be learned about how adults with I/DD age. Therefore, we would like to take this opportunity to fill the void in information. All of you are family members of residents of Sunshine Inc., and we would like to know your opinions on your loved ones ageing process and how we can help. You will have the most insight into how your family members have changed due to aging and how it has affects on your families.

We would like to remind you that all of your experiences will be different so there are no right or wrong answers. We are trying to gather basic information to better help your loved one's age successfully. The results that derive from this focus group will be used to fulfill my scholarly research project for my completion of a doctoral degree in occupational therapy.

I would like to share some rules before we begin with the discussion. When sharing comments, please speak clearly and only one person speak at a time. As I said before, we will be recording the session to make sure we hear all of your opinions and comments. Today, please use each other's first names only when addressing each other. However, your names will not be associated with your comments to protect your privacy and the privacy of everyone in the group. Also, please be aware that we are interested in positive comments but feel free to address negative ones, as growth most frequently comes from change. On a final note, please silence or turn off your cell phones. If you have an emergency or need to answer a call please do it in the hallway. We will be here approximately 90 minutes.

Now that I have introduced myself, let's go around and introduce each other. Please state your first name and relationship to your family member.

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Purpose

The purpose of this study is discover what role do family caregivers play in the lives of their adult loved ones with I/DD. We are also aiming to gather what the major issues affecting successful aging of adult children with I/DD are according to family caregivers. This current study will also describe how occupational therapy can help in successful aging of adults with I/DD.

Questions for the Family Members of Individuals with I/DD Focus Group

- 1.) Tell us a little bit about your loved one.
- 2.) What age related changes have you seen in your family member?
- 3.) How have those changes affected you and him/her?
- 4.) What is the main issue you are concerned with as your family member ages?
- 5.) Describe your opinion on what “successful aging” would mean for your family member with I/DD.
- 6.) How has your aging affected your family member?
- 7.) What would you need to help your loved one age successfully?
- 8.) How can occupational therapy help in successful aging of adults with I/DD?
- 9.) How can occupational therapy help you while caring for your loved one?
- 10.) What advice would you give to other family members like yourselves with family members aging with I/DD?

Closing

- a.) Verbalize a summary of the session and ask “Is this an accurate summary?”

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- b.) Give an overview of the events of the session and ask the group, “Did we miss anything?”

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Appendix E
Consent Form

IRB# _____

ICF Version Date _____



Occupational Therapy Program
Department of Rehabilitation Sciences
The University of Toledo
2801 W. Bancroft Street, Mail Stop 119
Toledo, Ohio 43614
Phone # 419-530-6696
Fax # 419-530-4780

**ADULT RESEARCH SUBJECT INFORMATION AND CONSENT FORM and
AUTHORIZATION FOR USE AND DISCLOSURE OF PROTECTED HEALTH
INFORMATION**

**Family Opinions of Their Adult Children with Developmental Disabilities Aging
Successfully**

Principal Investigator: Beth Ann Hatkevich, PhD, OTR/L

Co-Investigator: Barbara Kopp Miller, PhD
Hannah Robinson

Research Assistant: Nicole Johnson
Erica Frederick

Contact Phone number(s): (419) 530 6696

PURPOSE (WHY THIS RESEARCH IS BEING DONE)

You are invited to participate in the research project entitled Family Opinions of Their Adult Children with Developmental Disabilities Aging Successfully, which is being conducted at The University of Toledo under the direction of Beth Ann Hatkevich, Ph.D. The purpose of this study is to assess family members perceptions of the needs of their loved ones aging individuals with intellectual and developmental disabilities (I/DD). The data from this research will be used to develop ideas for future research, assessment, and intervention techniques for the population of aging individuals with I/DD.

DESCRIPTION OF THE RESEARCH PROCEDURES AND DURATION OF YOUR INVOLVEMENT

This research study will take place at Sunshine, Inc., located in Maumee, Ohio. This research session will meet only once, and it should take between 1 and 2 hours. There will be approximately 40 participants. You will be asked to discuss questions relating to issues in aging for individuals with intellectual and developmental disabilities. Audio recording is to be used, to ensure the accurate transcription of your comments.

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Permission to record: Will you permit the researcher to audio record during this research procedure?

YES NO

Initial Here

Initial Here

After you have completed your participation, the research team will debrief you about the data, theory and research area under study and answer any questions you may have about the research.

RISKS AND DISCOMFORTS YOU MAY EXPERIENCE IF YOU TAKE PART IN THIS RESEARCH

There are minimal risks to participation in this study, including loss of confidentiality. It is possible that you will become uncomfortable with sharing certain ideas or perceptions. It is also possible that you will disagree with one another during the session. You have the right to stop participating, either temporarily or permanently, at any point during the session.

POSSIBLE BENEFIT TO YOU IF YOU DECIDE TO TAKE PART IN THIS RESEARCH

The only direct benefit to you if you participate in this research may be that you will learn about how focus groups are run and may learn more about aging individuals with intellectual and developmental disabilities. Others may benefit by learning about the results of this research.

CONFIDENTIALITY

The researchers will make every effort to prevent anyone who is not on the research team from knowing that you provided this information, or what that information is. The consent forms with signatures will be kept separate from responses, which will not include names and which will be presented to others only when combined with other responses. Although we will make every effort to protect your confidentiality, there is a low risk that this might be breached.

VOLUNTARY PARTICIPATION

Taking part in this study is voluntary. You may refuse to participate or discontinue participation at any time without penalty or a loss of benefits to which you are otherwise entitled. If you decide not to participate or to discontinue participation, your decision will not affect your future relations with the University of Toledo or The University of Toledo Medical Center.

OFFER TO ANSWER QUESTIONS

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over. If you have questions regarding the research at any time before, during or after the study, you may contact Beth Ann Hatkevich, at (419) 530-6696 or BethAnn.Hatkevich@utoledo.edu; and Hannah Robinson at (330)321-2799 or Hannah.Robinson@rockets.utoledo.edu.

If you have questions beyond those answered by the research team or your rights as a research subject or research-related injuries, please feel free to contact the Chairperson of the University of Toledo Biomedical Institutional Review Board at 419-383-6796.

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SIGNATURE SECTION (Please read carefully)

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN THIS RESEARCH STUDY. YOUR SIGNATURE INDICATES THAT YOU HAVE READ THE INFORMATION PROVIDED ABOVE, YOU HAVE HAD ALL YOUR QUESTIONS ANSWERED, AND YOU HAVE DECIDED TO TAKE PART IN THIS RESEARCH.

BY SIGNING THIS DOCUMENT YOU AUTHORIZE US TO USE OR DISCLOSE YOUR PROTECTED HEALTH INFORMATION AS DESCRIBED IN THIS FORM.

The date you sign this document to enroll in this study, that is, today's date, MUST fall between the dates indicated on the approval stamp affixed to the bottom of each page. These dates indicate that this form is valid when you enroll in the study but do not reflect how long you may participate in the study. Each page of this Consent/Authorization Form is stamped to indicate the form's validity as approved by the UT Biomedical Institutional Review Board (IRB).

Name of Subject (please print)	Signature of Subject or Person Authorized to Consent	Date a.m. p.m.
Relationship to the Subject (Healthcare Power of Attorney authority or Legal Guardian)		Time
Name of Person Obtaining Consent (please print)	Signature of Person Obtaining Consent	Date
Name of Witness to Consent Process (when required by ICH Guidelines) (please print)	Signature of Witness to Consent Process (when required by ICH Guidelines)	Date

YOU WILL BE GIVEN A SIGNED COPY OF THIS FORM TO KEEP.