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EXPANDING UNIVERSAL DESIGN APPLICATIONS WITHIN RESIDENTIAL HOMES
TO MAXIMIZE PERSON-ENVIRONMENT FIT FOR CHILDREN WITH INTELLECTUAL
DISABILITIES AS THEY AGE IN PLACE.

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EXPANDING UNIVERSAL DESIGN APPLICATIONS WITHIN RESIDENTIAL HOMES
TO MAXIMIZE PERSON-ENVIRONMENT FIT FOR CHILDREN WITH INTELLECTUAL
DISABILITIES AS THEY AGE IN PLACE.

A THESIS APPROVED FOR THE
CHRISTOPHER C. GIBBS COLLEGE OF ARCHITECTURE

BY THE COMMITTEE CONSISTING OF

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Dedication

To all those with intellectual disabilities, may you never know the injustices of the world. Let your light shine bright and show the rest of us the way.

Acknowledgments

I am deeply humbled by the support and commitment shown to me by my committee: Dr. Natalie Ellis, Dr. Suchismita Bhattacharjee and Tracy Scott-Howard. I have learned so much from each of them, and I admire their dedication to the process, especially these last few months as we all have experienced uncertainty and dramatic changes within the world.

Isaiah 40:31 – but they who wait for the Lord shall renew their strength; they shall mount up with wings like eagles; they shall run and not be weary; they shall walk and not faint.

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Terms and Definitions

<u>Adolescent Adults</u> – are dependents over the age of 19, diagnosed with an intellectual disability that has resulted in delayed learning and cognitive impairment, and typically live with a caregiver.

<u>Aging in place</u> – living out one's life in the place of their choosing, most commonly in a single-family residential home.

<u>Autism</u> – a developmental disability that can cause significant social, communication and behavioral challenges (CDC, Autism Spectrum Disorder, 2020).

<u>Caregiver(s)</u> – a family member providing direct and indirect care to a relative with an intellectual disability (Ryan et al., 2013). For the purpose of the study, caregiver is interchangeable with parent.

<u>Down Syndrome</u> – a genetic condition with an extra copy of chromosome 21 that alters physical and intellectual development.

<u>Epileptic Encephalopathy</u> – severe brain disorder at an early age involving seizures, and deficits in cognitive, behavioral and neurological characteristics.

<u>High Functioning</u> – an informal term use to describe the level autonomy and reading, writing, communication and life skills of individuals with intellectual disabilities.

<u>Intellectual Disabilities</u> – is the terminology used to describe an individual's ability to learn and develop daily life functions (CDC, Developmental Disabilities, 2019).

<u>Intelligence Quotient</u> – a number representing a person's reasoning ability (measured using problem-solving tests) as compared to the statistical norm or average for their age, taken as 100 (Lexico, US Dictionary, n.d.).

<u>Quality of life</u> - the standard of health, comfort and happiness experience by an individual or group (Lexico, US Dictionary, n.d.).

<u>Universal Design</u> – is the design of products and environments to be usable by all people, to the greatest extent possible, without adaptation or specialized design (Connell, et al., 1997).

<u>Vanishing White Matter</u> - (VWM) is a genetic disorder that affects the nervous system and causes neurologic symptoms.

Abstract

Children with intellectual disabilities often have specified needs that could potentially benefit from design modifications to the home. The study's purpose is to identify the design challenges that can be held within single-family residential homes from the perspective of the primary caregivers of children with intellectual disabilities. The participating caregivers provide a voice for the children with varying diagnosis, level of autonomy and range of abilities. Among the caregivers interviewed, three common themes emerged: 1) keeping the child safe, 2) maintaining a sense of normalcy and 3) providing an appropriate level of independence or autonomy. The seven principles of universal design were then evaluated within the three categories to determine the correlation of person-environment congruence within single-family residential homes. The research supports design considerations that align with the needs of individuals with intellectual disabilities living in multi-generational; single-family homes, including home renovations and new home construction, inclusive of the furniture, fixtures and equipment (FF&E). The study incorporates prior research relevant to occupants diagnosed with intellectual disabilities, and new information was gathered from the study's participants during face to face interviews. Due to the limited number of participants and the variety of intellectual disabilities represented, the results of this qualitative study cannot be generalized; however, the research follows an emergent design process that provides a framework process for future knowledge and policy contributions.

Key words: Intellectual disabilities, single-family residential homes, multi-generational families, aging in place, universal design, ADA, inclusive, caregivers, safety, normalcy, independence. Person-environment congruence

CH 1. INTRODUCTION

According to the Centers for Disease Control and Prevention (CDC), 1 in 4 adults in the

United States lives with a disability (CDC, Newsroom, 2018). Additionally, the CDC has

reported a 1.6 % increase of children diagnosed with an intellectual disability (ID) within the last

decade (Bitsko et al., 2019; CDC, 2019). A study conducted between 2015-2017, by the CDC

and the Health Resources and Services Administration (HRSA), revealed 17 % of children

between the ages of 3 to 17 have been diagnosed with an intellectual disability. According to the

American Association on Intellectual and Development Disabilities (AAIDD), "intellectual

disability is a disability characterized by significant limitations in both intellectual functioning

and in adaptive behavior, which covers many everyday social and practical skills" (AAIDD,

2020).

Children with intellectual disabilities often have specified needs that could potentially

benefit from design modifications to the home to include accessibility and universal design

practices. The study's purpose is to identify the design challenges that can be held within single-

family residential homes from the perspective of the primary caregivers of children with

intellectually disabilities. Children diagnosed with intellectual disabilities may require lifelong

care, and often they remain under the primary care of their parents in the family home. These

children are now living past the age of 50, and they can likely outlive their primary caregivers

(Burke et al., 2016; Zigman, 2013).

Despite this statistical knowledge, single-family residential homes continue to be built

with very little consideration given to accessibility needs or universal design practices. The

United States Access Board (USAD, Guide to ADA standards, 2020) states that private single-

family residential homes are not subject to any of the ADA standards required in public and

federal facilities; therefore, accessibility and universal design practices are left to the discretion of the architects, builders, interior designers and homeowners. The design community has recognized the benefit of expanding residential design beyond minimum building requirements, but the National Association of Home Builders (NAHB) considers implementation of design regulations to be cost prohibitive to builders and the homeowners (NAHB, 2020).

The current qualitative thematic research is centered around the theory of person-environment congruence or the degree of fit between two sets of variables (Monahan & Muchinsky, 1987). Monahan and Muchinsky (1987) state there are two types of person-environment congruence: supplementary and complementary. Supplementary congruence is the match between an individual (child with intellectual disability) and a group of people (caregivers) that make up an environment (family unit). For the purpose of this study, the family unit as a whole would be the environment comprised of the child relationship to the caregivers illustrated in figure 1.

Figure 1: Supplementary Congruence
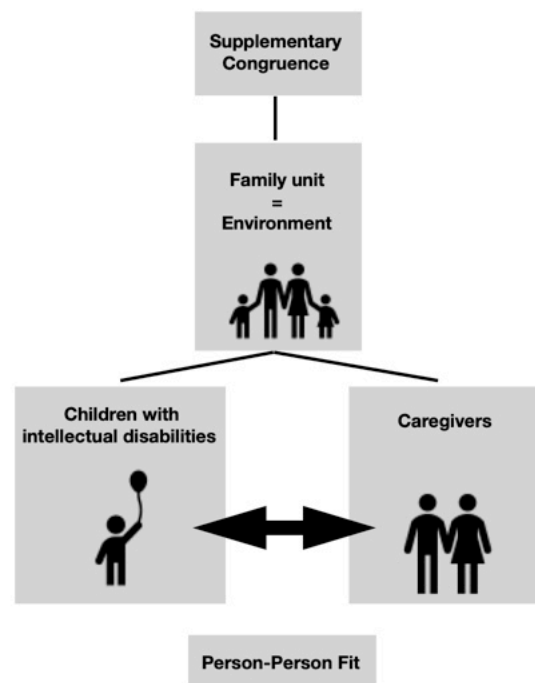
The second type of person-environment congruence is complementary congruence (Monahan & Muchinsky, 1987). Complementary congruence is the match between the collective abilities of the family unit (referenced in figure 1), and the corresponding physical environment (single-family residential home). The data collected in the current study revealed design challenges in the physical environment (single-family residential home) that negatively impacted complementary congruence. The primary caregivers voluntarily participated in face-to-face interviews, their responses were coded into three main areas of concern within the physical environment: 1) keeping the individual safe, 2) maintaining a sense of normalcy and 3) providing an appropriate level of independence or autonomy. The principles of universal design, combined with the knowledge gained from the caregivers, provide valuable insight into designing single-family residential homes that support complementary congruence of the family unit (illustrated in figure 2). Currently, the caregivers are left to their own creativity and limited resources to provide design solutions and modifications within the home.

Figure 2: Complementary Congruence
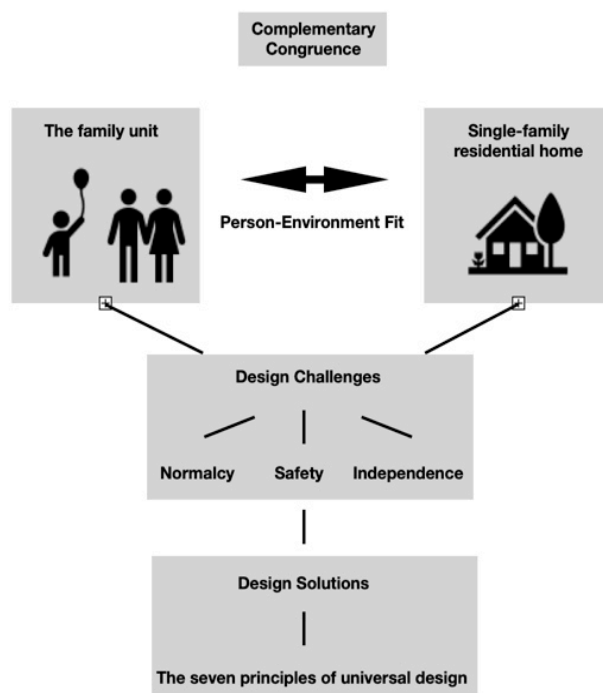
Research Goal

The study's primary goal was to identify design challenges withheld in single-family residential homes from the perspective of the primary caregivers of children with intellectual disabilities (ID). The seven principles of universal design were then used as a guide to identify and provide design solutions that can be incorporated into existing home renovations and new home construction, inclusive of the furniture, fixtures and equipment (FF&E). The research questions presented for the study are as follows: 1) What design challenges can be withheld in single-family residential homes from the perspective of the primary caregivers of children with intellectual disabilities, and 2) Which of the seven Principles of Universal Design aid the growing population of multi-generational families living with children with intellectual disabilities?

Research method

The current study benefited from a thorough literature review of intellectual disabilities to include characteristics, attributes and history of care. The literature review also provides examples of co-design or participatory design. Participatory design is a technique that allows interior designers and architects to learn directly from the users through dialogue and behavioral observation (Farhin & Sitbon, 2017). This technique is of particular interest when designing for individuals with intellectual disabilities. Similar to Farhin and Sitbon (2017), participatory design was incorporated into the current research in the form of face-to-face semi-structured interviews with the caregivers. The informal process follows the Emergent design research method that allows the outcome to evolve and change direction based on the information collected (Creswell & Creswell, 2018). The interviews provided pertinent information concerning residential design challenges from the perspective of parents of children with

intellectual disabilities. The information gathered from the parents was coded using Braun and Clarke's (2006) six steps to Thematic analysis. The coding process allowed the researcher to cluster data into three themes: 1) safety, 2) normalcy, and 3) independence. The three themes were then evaluated using the seven principles of universal design to determine which principles interior designers and architects should implement into single-family residential homes.

Initial contact with the study's participants was through a local non-profit support group - *The Sparrow Project. The Sparrow Project*, based in Moore, OK, provides on-going life skill learning and development through a variety of activities conducted in a safe environment for post high school adults with intellectual disabilities. The study's participants were parents and primary caregivers of adult children with intellectual disabilities. The participants voluntarily agreed to answer questions in-person using a semi-structured interview process. The interview consisted of eight structured questions for consistency between participants in the study. The first four questions were structured and provided basic demographic information, and the last four were open-ended questions focused on design challenges met within the single-family residential home. The encompassing semi-structured interview followed the emergent design research method as an informal process that encouraged deviation and open conversation with the participants. Each participant was encouraged to share their own unique perspective, and the information was collected and coded into themes by the principle investigator.

Study Participants

The study participants consisted of parents caring for at least one child diagnosed with an intellectual disability. These children are currently living at home and will likely age in place under the care of the parents. All but two of the children are over the age of 18 and have aged out of the public-school system.

The qualitative study's purpose is to identify the primary design challenges experienced within a single-family residential home from the perspective of the primary caregivers of dependent adult children with intellectual disabilities. The interview results identified a variety of structural challenges in which design modifications support person-environment congruence to both the caregiver and the dependent adult children with intellectual disabilities (ID). The interviews also revealed design challenges inclusive of the furniture, fixtures and equipment (FF&E). The recommended design modifications are supported by the principles of universal design and will be further discussed within the study. The literature review supports individuals with intellectual disabilities living at home with a parent or primary caregiver over institutional care for learning, development and overall quality of life. The study aims to provide design solutions that enhance quality of life for individuals with intellectual disabilities while adhering to the principles of universal design.

CH 2. LITERATURE REVIEW

Users of Universal Design

The Americans with Disabilities Act (ADA) provides minimum design requirements that are enforceable standards of accommodation in commercial facilities and state and local government buildings, primarily serving those with a physical disability (USAD, 2020). Universal Design is not mandated, but it was created to serve the broadest of users regardless of age, size or abilities, including those diagnosed with an intellectual disability. The purpose of this research is to understand the environmental challenges experienced by those with an intellectual disability and determine if Universal Design applications are beneficial within the residential home. Intellectual Disability (ID) is an umbrella term used to group a wide range of diagnosis, including autism, Down syndrome, epileptic encephalopathy, vanishing white matter and many other intellectual disabilities. According to the Centers for Disease Control and Prevention (CDC), ID is the terminology used to describe an individual's ability to learn and develop daily life functions (CDC, Developmental Disabilities, 2019). The Individuals with Disabilities Education Act (IDEA), defines ID as "significantly sub-average general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance," (IDEA, 2020). The American Association on Intellectual and Developmental Disabilities (AAIDD) further explains intellectual functioning to include learning, reasoning and problem solving related to general mental capacity, and adaptive behavior includes conceptual, social and practical skills that are learned and practiced daily (AAIDD, 2020). Conceptual, social and practical skills are further detailed in figure 3.

Figure 3: Adaptive Behavior

(AAIDD, 2020)

> **Conceptual skills**–language and literacy; money, time, and number concepts; and self-direction.
> **Social skills**-interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness, social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
> **Practical skills**-activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

Why is universal design important?

Universal design provides a framework of recommended accommodation guidelines for builders, architects and interior designers to consider as they navigate the creative process towards a widely usable product or environment. Universal design in practice has predominantly been driven by the desire of people to age in place as they chronologically live longer, subsequently avoiding the expense and the transition to a nursing home. Architect, Ron Mace coined the term universal design, a concept Mace described as an approach to designing products and the built environment to be aesthetic and usable to the greatest extent possible, regardless of the users age, ability, or status in life (Jones, 2010; Mace, 2008;). Mace, having spent most of his life in a wheelchair, experienced firsthand the challenges of barrier-free and accessible design. However, he is most known for his contributions to universal design. In 1997, Mace lead a team of architects, designers, engineers and researchers at *The Center for Universal Design* at North Carolina State University. The team collectively established the following definition: "Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without adaptation or specialized design" (Connell et al., 1997). Adaptation and specialized designs are commonly associated with the Americans with Disabilities Act (ADA) and accessibility compliance requirements. A good example of universal design building upon ADA standards can be experience at the Southwest airline terminal at

William P. Hobby Airport in Houston, Texas. According to the 2015 International Building

Code (IBC), Chapter 11 Accessibility, Section 1109 Other Features and Facilities, two drinking

fountains are required when placed into public spaces. One fountain is to be mounted at standing

height (between 38 to 43 inches from the floor), and the other fountain is to be mounted at

accessible height (a maximum of 36 inches from the floor) to accommodate wheelchair users

(ICC, 2015). However, in the Hobby airport, the designers exceeded the minimum ADA

requirements by providing additional user options as shown in Figure 4. One fountain is

mounted lower than accessible height allowing children to drink independently without being

lifted by a parent. The lower height can also accommodate people with dwarfism. An additional

fountain is mounted at an above standard height for people of taller stature,

Figure 4: Drinking fountains at Houston Hobby airport

(Huff, 2017)

allowing the users to bend over at a more comfortable level. IBC further explains in section

1109.5.2 that when the minimum number of drinking fountains is exceeded, then the accessible

height fixtures should represent 50 percent of the total. In this example, the accessible height

fountains only represent 40 percent of the total; however, IBC provides an exception if the child

height fountain is mounted a minimum of 30 inches above the floor (ICC, 2015).

Intellectual Disability Attributes and Classifications

Mental abilities and adaptive skills are the two main attributes used to determine if a

child has an intellectual disability (Fenell et al., 2020). An intellectual functioning test (IQ)

measures these two functioning aspects, intellectual functioning and independent functioning.

The first attribute measures values and those below 70 are marked as having a cognitive

impairment. The second is the capacity to function independently, also referred to as adaptive

behavior (Fenell et al., 2020). According to Fenell et al., (2020), early indications of an

intellectual disability include a delay in walking and talking, lapses in memory, difficulty

relating actions to consequences, and the inability to problem solve. IQ testing was first

introduced in 1911 by the French psychologists, Alfred Binet and Theodore Simon. The

formalized IQ classification system included: Gifted = above 130, Normal = above 70, Morons =

50-70, Imbeciles = 26 to 50, and Idiots = 0 to 25 and was used until the early 1970s. The Moron,

Imbecile and Idiot classifications have since been replaced with mild (50-70), moderate (35-55),

severe (20-40) and profound (0-25) (Gold, 2011). The term mental retardation remained the

diagnosis standard until 2012, when the United States federal government ordered the use of the

term to be changed to intellectual disability because it was considered to be less offensive and

more inclusive (Fenell et al., 2020).

Intellectual Disability Causes

Intellectual disabilities can occur any time prior to the age of 18. Genetic conditions,

birth defects, and infections that occur prior to birth, during birth or soon after birth are common

examples (CDC, Developmental Disabilities, 2019). Other known causes of ID might include

disease and exposure to toxins such as lead and mercury, serious head injury, stroke, or certain

infections (Developmental Disabilities, 2019, Fenell et al., 2020). In the United States, 1.3

million people live with some form of intellectual disability (Anderson et al., 2014). Down

syndrome (DS) is diagnosed in about 1 in 700 live births and DS is one of the most recognized

ID conditions, followed by moderate autism as the second most recognized intellectual disability

(Canfield et al., 2010; Power, 2008).

Care History

In the 1920s, the median lifespan for someone with Down syndrome (DS) was 9 years

(Penrose, 1949), and by the 1980s the lifespan grew to 25-30 years (Burke et al., 2016).

Currently, in the 21st century, the life expectancy for someone with DS has grown to 50-60 years,

nearly a 40% increase, and the population with ID as a whole has increased in age by more than

fifty years, especially among those with mild cognitive impairment (Ryan et al., 2013). The

trend of enhanced longevity is expected to continue, and it is credited in part to changes in

lifestyle, and the advancements in technology and modern medicine, (Burke et al., 2016;

Jennings, 1987; Santulli, 1954). As the population continues to age in place, designers and

architects have the opportunity to expand the use of universal design aspects into residential

living environments.

Institutional Care

In the late 1940s and early 1950s, parents rarely took a child with and intellectual

disability home from the hospital. Instead, a child would be taken away from the mother within

the first few days of life, and then the child would be institutionalized, often by the

recommendation of the attending physician (Aldrich, 1947; Bard & Fletcher, 1968). The rational

for institutional care versus home care was fueled by a belief system that the infant's impact on the family unit (supplementary congruence) would be disruptive and traumatizing (Antommaria, 2006; Granquist, 2009).

Home Care

Over the past century, institutional care for children with Intellectual Disabilities (ID) has been phased out in favor of home care, and it is estimated that 75% to 84% of persons with ID live with family or a health care provider (Burke et al., 2016). In the 1950s and 1960s, several studies support the concept that children with ID raised at home by a parent was preferred over children cared for in institutions (Yannet, 1953). One study, conducted in 1959, compared the development of children with Down Syndrome (DS) raised in a home setting by their parents to the children with DS raised institutionally. The study concluded that the children raised at home were more advanced than those raised in an institutional setting (Kugel & Reque, 1961). The children had developed motor skills, walked and talked at an earlier age, including short sentence development of three or more words (Antommaria, 2006; Kugel & Reque, 1961). The findings from Kugel & Reque (1961) support home care over institutional care especially during the early formative years; however, they do not address caring for dependent children as they transition into adulthood and live out their years in the home. An adult with an intellectual disability, aging in place, will continue to learn and develop life skills in a supportive environment; and the parents, as primary caregivers, should be viewed as a valuable resource of information for designers to further develop universal design within the residential home. Involving caregivers is a co-design method used by Farhin and Sitbon (2017). The caregivers provide a voice, bridging the communication gap between the participants with intellectual disabilities and the researchers.

Caregivers

Individuals with intellectual disabilities experience a high sensitivity to transitions (Hamilton et al., 2005); and therefore, they are more likely to live with a family member rather than owning their own home or live in an institution (Bershadsky et al., 2012). In 2004, the Taiwanese government supported a new program that provided small group housing for adults with ID in order to allow for maximized autonomy. Unfortunately, many did not transition well, and therefore, returned home to the parental caregivers (Chang et al., 2011). Additionally, adults with ID typically do not marry and therefore are reliant on a parent or sibling to provide care as they age (Ryan et al., 2013).

Perpetual Parenting

Until recent years, parents typically out lived their intellectually disabled children. However, as the life expectancy of someone born with an intellectual disability is approaching 60 years of age, they are likely to out-live their parent(s) or predominate caregiver(s) (Burke et al., 2016). Parents of ID children typically view perpetual parenthood or permanence care as their responsibility. Perpetual parenthood is defined as parents that have been living with an adult offspring since the child's birth (Botsford & Rule, 2004; Jennings, 1987). A literature review conducted by a team of researchers and medical professionals revealed that most people with ID and their caregivers wanted to age in place together despite the likely hood of the ID child outliving his/her parents (Ryan et al., 2013). A child with ID that out-lives his or her parent(s) will likely experience loss of identity and autonomy, reduced coping capacity, and an increased risk of depression, dementia and Alzheimer's (Botsford & Rule, 2004; Burke et al., 2016). For these reasons, the parents are known to experience feelings of guilt, and do not want to pass on the unfair burden of care to the other siblings (Black & McKendrick, 2010).

Sandwich Generation

The 21st century has also introduced a new level of family caregivers, referred to as the sandwich generation. This group of caregivers is best described as adult offspring raising young children while also providing care for their aging parents (Boyczuk & Fletcher, 2016). However, add in an intellectually disabled sibling, and it becomes the triple-decker of caring for their aging parent(s), their own children, and their brother or sister with ID (Burke et al., 2016).

As individuals with intellectual disabilities mature in age beyond 18, they no longer have the resources provided by their local public-school systems to aid in further learning and development of life skills. These children age out of the system, and the entire burden of care is shifted to the primary caregivers. Many of the caregivers are left with no other choice than to quit their jobs and stay at home to provide care.

All of the circumstances described above involve multiple generations living and aging in place together. The population of aging children with intellectual disabilities tends to be higher functioning, and they embrace independent choices tailored to individual physical and mental abilities.

Universal Design integration into single-family homes

Exploring universal design residential home applications could aid the growing family group that have children diagnosed with Intellectual Disabilities (ID). The combination of extended life and the burden of care has resulted in a growing need for residential design options that support multi-generational families living with an intellectually disabled dependent. The ID community is unique and deserving of quality of life, "the standard of health, comfort and happiness experience by an individual or group" (Lexico, US Dictionary, n.d.). Universal design applications could potentially improve the quality of life for both the caregivers and the

dependent adults that are aging in place in multi-generational single-family homes. Interior designers and builders can help this growing population to age in place by providing applicable design solutions rather than leaving the occupants to adapt to the existing environment or resort to creating their own solutions. Designing for the increasing population with intellectual disabilities will require an active and inclusive approach by the builders and interior designers to gain knowledge of family practices in the home to include rhythms, routines, and social activities (Power, 2008). Inclusive design builds upon universal design concepts and will be discussed further as part of this study.

How is universal design currently being addressed?

The primary driver of universal design has been the aging population around the globe. Japan is the leader of this growth trend with more than 26% of its population being 65 years of age or older. The numbers are steadily rising each year, and by the next decade almost a third of the Japanese population will be senior citizens (Haider, 2017). Consequently, Japan has emerged as the leader of innovative products and design strategies that embody universal design principles. Japan is the first Asian country to persuade its general public to accept universal design principles for residential environments, and they may be the only country to use economic incentives to address the implications of a rapidly aging society (Jones, 2010). The two primary residential design choices widely accepted include level floor bathrooms and bidet toilets (Kose, 2003). Outside of Japan, universal design remains a niche concept still confused with accessible design among practicing professionals and modern-day students of architecture and design (Fletcher, 2010).

Universal design does include accessible and barrier-free design; however, unlike ADA, universal design is not mandated. ADA is a minimum performance guideline that is often

incorporated into building codes which typically are also minimum performance. Universal design avoids the look and feel of a clinical environment, and the use of medical equipment and assistive technology (Mace, 2016). For example, a wheelchair lift on a staircase and an elevator are two different methods used to vertically transport people. The wheelchair lift is classified as assistive technology specific to a small group of users. However, the elevator would be an example of universal design since it was originally created to vertically transport large items and people. While a wheelchair user can use both methods to transfer between stories, the elevator is designed to be accessible to nearly all users with the ability to operate by pushing buttons while standing or sitting. Typically, the elevator is also more aesthetically pleasing than the wheelchair lift system.

In many instances, universal design is not unique, and may only require slight modifications to things, such as the size, shape, or even the placement of an item. As shown in figure 5, two identically designed chairs are place side by side in an orthopedic office waiting

Figure 5: Chairs in orthopedic waiting room

(Huff 2018)

room. The chair on the left would be considered a standard size, while the chair on the right is

clearly wider and it will accommodate a larger person. Additionally, the wider chairs were

sprinkled throughout the waiting room allowing family members of various sizes to sit next to

each other comfortably. Universal design is best understood when broken down into the *Seven*

Principles of Universal Design listed in figure 6.

Figure 6: The Seven Principles of Universal Design

(Connell, et al., 1997)

The Seven Principles of Universal Design

1) Equitable use - the design is useful and marketable to people with diverse abilities

2) Flexibility in use – the design accommodates a wide range of individual preferences
and abilities.

3) Simple and intuitive use – use of the design is easy to understand, regardless of the
user's experience, knowledge, language skills, or current concentration level.

4) Perceptible information – the design communicates necessary information
effectively to the user, regardless of ambient conditions or the user's sensory abilities.

5) Tolerance for error – the design minimizes hazards and the adverse consequences of
accidental or unintended actions.

6) Low physical effort – the design can be used efficiently and comfortably and with a
minimum of fatigue.

7) Size and space for approach and use – appropriate size and space is provided for
approach, reach, manipulation, and use regardless of the user's body size, posture,
or mobility.

Mace (1998) explains that the handicap stall is also an example of how making

something larger makes the space usable by more people. The extra wide toilet space is

currently referred to as an accessible stall required by the ADA in public restrooms to provide

access to those using a wheelchair. The larger stall design also provides added comfort and

convenience for people traveling with luggage, or shopping with a small child in a stroller, creating a safer environment for users to keep track of their belongings (Mace, 1998).

Why shouldn't we be satisfied with current approaches?

In Mace's last speech (1998), he shared a personal experience of ADA design that was not universal design. He attempted to stay at a hotel that was ADA compliant with accessible rooms on each floor. However, the rooms were continuous (e.g., 503, 603, 703) up the tower. All of the accessible rooms provided only for left-handed transfers onto the toilet, but Mace made a right-handed transfer. Since ADA did not require left-handed and right-handed rooms, this hotel was not universally accessible for wheelchair users (Mace, 1998).

What do we know about universal design?

Universal design (UD) is intended to serve a broader population, and the primary focus of UD is on the user's physical interaction with the environment (person-environment congruence), while less emphasis is placed on the user's emotional response or experience. Individuals with an intellectual disability tend to have an emotional connection to an environment, and they often communicate thru behavior rather than words. Designing for an emotional connection in addition to physical interaction can be challenging for interior designers and architects.

Designers and architects recognize the existence of a two-way relationship between the built environment and the end user known as complementary congruency; however, post occupancy reviews have revealed that the intended outcome can be quite different when actually experienced. A study, conducted at museum M in Louvain, Belgium, aimed to compare the intended result of the architect, Stèpane Beel, to the actual experience of participants with a physical disability or sensory impairment. Beel, and his team, had paid explicit attention to persons with disabilities throughout the entire design process, and one of the design goals was to

create an entrance, aimed at physical inclusion to allow for wheelchair users and able-bodied

people to enter together without separation (Helighen et al., 2013). Beel's innovative design

combined the stairs and the ramp, creating an entrance that was considered to be "very easily

accessible" (Helighen et al., 2013). Two participants were used in the study, one in a wheelchair

(Charlotte) and the other was visually impaired (Phillip). The results of the study were based on

Charlotte and Phillip's experience, and their areas of concern included the following listed in

figure 7.

Figure 7: Areas of Concern

(Helighen et al., 2013)

Areas of Concern:
1. The banister for the stairs was not continuous due to the ramp crossing the stairs. Break in banister shown in figure 8.
2. From street level the descending entrance of ramp and stairs appear as one continuous white incline plane. Street level shown in figure 9.
3. The direction of the ramp is only indicated by dots in the middle of the large ramp stones. Wayfinding dots shown in figure 8.

Figure 8: View of street level entrance from bottom

(Helighen et al., 2013)
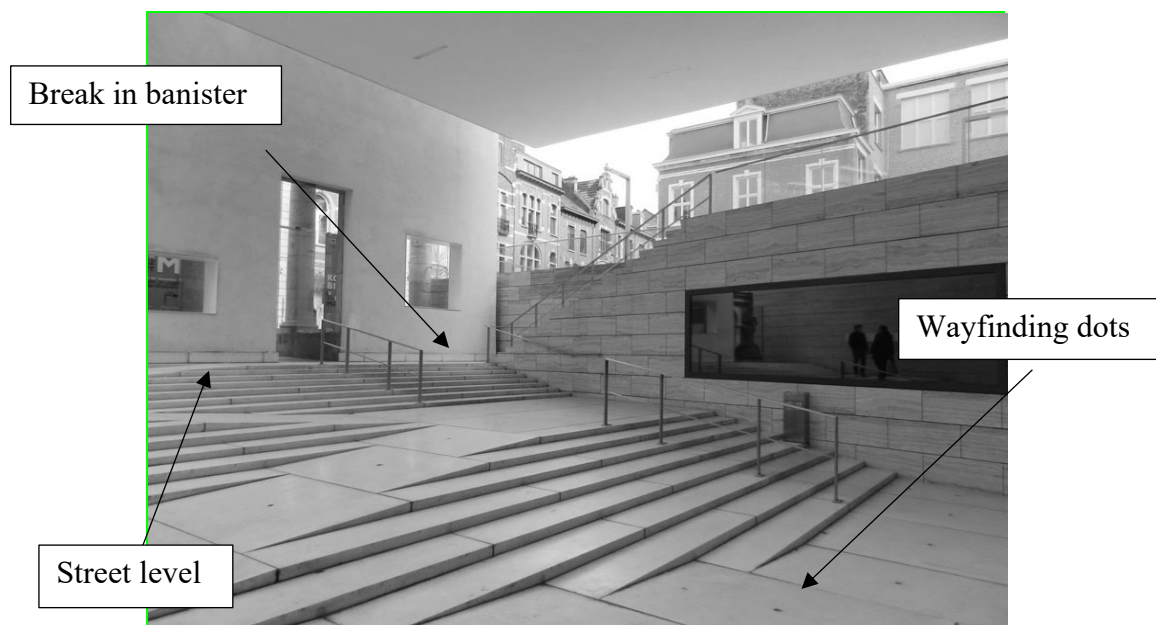
Figure 9: View of entrance descending from street level

(Helighen et al., 2013)

Phillip and Charlotte noticed that they felt annoyed, scared, and confused when trying to navigate the descending entrance from street level. However, their feelings do not constitute a failure in part to the design team, instead they reiterate that the actual experience can vary from the intent of the design.

The study's results could also be further considered by using the seven principles of universal design. The entrance design did meet the following four listed principles:

- 1) Equitable use

- 2) Flexibility in use

- 6) Low physical effort

- 7) Size and space for approach and use

However, one could argue based on the areas of concern experienced by Phillip and Charlotte that three of the principles did not meet the intended criteria, including the following:

- 3) Simple and intuitive in use

- 4) the design lacked Perceptible information

- 5) Tolerance for error.

While Phillip is visually impaired, the interruption of the banister caused uncertainty, and a fear of falling as he navigated down the stairs/ramp of the entrance. Both participants expressed that from the top of the incline, the continuous color made it difficult to distinguish the ramp from the stairs. The lack of clarity in space's building elements could result in several hazardous outcomes based on ones' false perception of the space. Lastly, Charlotte did not initially understand the use of dots as a method of wayfinding. The addition of signage and a variation in floor color would improve wayfinding and reduce fears of falling. Both Phillip and Charlotte were able to articulate their physical and emotional experience and provide useful insight into the actual experience verses the intended outcome of Beel's inclusive design.

The concept of inclusive design builds upon universal design through accommodations in the built environment that avoid separating or stigmatizing people with disabilities (Davy, 2015). The inclusive playground is a great example of an environment that is designed to eliminate both physical and social barriers for children. Socialization between all children is a critical element to the success of an inclusive playground and its equitable use. A well-designed inclusive playground focuses on the following five elements: Social/emotional play, physical play, sensory play, cognitive play, and communication for children with all abilities (Playcore, 2010). Additionally, there should be spaces available for large and small groups, solitude, quiet, and active play. By providing a variety of appropriate play spaces, children have the opportunity to develop self-confidence and social skills through interaction with other children with diverse abilities. Children inherently learn at an early age to gather information through the use of their senses. Therefore, a design that includes the ability to explore utilizing sight and sound as well as smell and touch will provide a more inclusive experience for all children (Playcore, 2010).

The design elements and principles utilized in inclusive playgrounds could provide in-site for future residential design that is inclusive for individuals with intellectual disabilities living in multi-generational single-family homes.

Learning directly from those living with intellectual disabilities is another approach towards inclusive design. By considering those with ID the experts of their circumstance, interior designers and architects can expand knowledge and creativity towards future home designs. A recent study conducted in Liège, Belgium, focused on the inclusion of Down Syndrome occupants as a means to creating a successful design process. The study recognizes that designers struggle with the inclusion of physically disabled people due to the broad spectrum of disabilities, and cognitive impairments are even more so neglected during the design process (Elsen & Schelings, 2017). The Liège study credited the six Down syndrome participants as the experts and a source of creativity for designers (Elsen & Schelings, 2017). This study used an in-situ method of observation as a technique to learn the spatial perceptions of people with Down syndrome and how they interact with architecture. The four prominent behaviors that were observed during the study are listed in figure 10.

Figure 10: Four prominent behaviors

(Elsen & Schelings, 2017)

Four Prominent Behaviors
1. The participants experienced difficulty in identifying the limits between spaces that were not clearly delineated by a physical boundary.
2. The participants have a need for personal space.
3. The participants demonstrated an attraction for light, bay windows, illuminated objects and surfaces.
4. Material landmarks were important to the participants in regard to their day-to-day rituals and habits.

The participants did not experience complementary congruence within the environment when the physical boundaries between spaces were not clearly delineated. In contrast, the use of material

landmarks provided a positive connection to the environment that supported day to day rituals and habits. Complementary congruence with the environment was also achieved when the participants had access to personal space, as well as illuminated objects and surfaces.

While the Liege study should not be used by architects and designers as a generalized tool to design residential homes for people with Down syndrome, the study does recognize the participants to be experts of their disability and relevant to inclusive design. The concept of building on universal design through the utilization of inclusive design influenced the current research process.

Similar to the Liège study, the parents of children with intellectual disabilities are the most familiar with the rhythms, routines, and social activities practiced within the home; and therefore, considered to be the experts and the best resource for the current research.

Conclusion

It should be noted, that while change is slow, there has been significant advancements made over the last 70 years. Children with intellectual disabilities are living longer lives with various levels of independence. Terminology clarifications and changes, and federal protections mechanisms have allowed progress to be made in areas of social inclusion. These changes provide the opportunity for further advancements and creation of new living options that include universal design implementation within the single-family home. The combination of extended life and the burden of care has resulted in a growing need for residential design options that support person-environment congruence in multi-generational families aging in place with a dependent child with ID. The continuous living experience is supported by inclusive research, and the seven principles of universal design. To date, much of the research and resources have focused on childhood development within the family home. The gap for caregivers begins when

a child graduates out of the school system leaving the caregivers with limited local resources including developmental activities and residential living options. Small regional studies could identify what resources are currently available and what resources are still needed to further support learning and development to include independence. Designers and architects can positively impact the future of residential design through practices of inclusion to expand knowledge and creativity within the design process.

CH 3. METHODOLOGY

Children with intellectual disabilities are living past the age of 50, and there is a strong likelihood that many will outlive their primary caregivers – predominately their parents (Hodapp et al., 2016). As adults with intellectual disabilities (ID) age and outlive their caregivers, it is important to understand the factors and influences that have positively and negatively affected their development and overall quality of life, while maintaining the security, comfort and familiarity experienced within the family home. The information gathered from the caregivers will be used to recommend universal design options that support complementary congruence while aging in place and to assess universal design consideration for future policy making.

In Person Interviews

A thematic qualitative study with a focus on social/behavioral research was conducted with the primary caregivers of dependent adult children with intellectual disabilities. The research method adopted the philosophy of participatory design practices for people with intellectual disabilities presented by Farhin and Sitbon (2017). Farhin and Sitbon involved the caregivers and valued their direct insights; additionally, the caregivers provided a voice for the individuals with limited communication skills. A semi-structured interview consisting of eight questions (four structured and four open ended), a verbal script and a consent form were developed (see Appendices) and submitted to the University of Oklahoma Internal Review Board (IRB) for approval. Research participants signed the consent form prior to beginning the interview, and all participants were asked the same set of questions to maintain consistency within the research. At any point during the interview the participant could choose to stop or end the interview without penalty. To keep participant data confidential, the interviewer numbered the interview question forms used to take notes during the interviews. Two of the participant

groups had multiple adult children with disabilities in the home. Therefore, multiple forms where used to take notes specific to each adult-child and were subsequently numbered and lettered (i.e. 3a., 3b., etc.). The informal, semi-structured interview process allowed the interviewer to gain the trust of those being interviewed while gathering data specific to the research. The informal interview process was intentional and follows the emergent design research method that supports deviation and open conversation to discover other relevant topics of interest to the research. In addition to taking detailed notes, the interviews were recorded (audio only) as approved by IRB. The interview process required an investment of time by the interviewer and the participants, but it is the belief that in person interviews would increase the quality of information gathered and contributed to the Emergent Design ideology (O'Leary, 2017). The study's primary focus was on the care provided to adult children with mild to moderate intellectual disabilities, while living at home with parents or siblings as primary care givers. Individual interviews with the primary caregivers were conducted at neutral locations to avoid unexpected demographic bias that could be associated with neighborhoods or economic living conditions.

Method of Contact

Initial contact with participants was through a local non-profit support group - *The Sparrow Project*. *The Sparrow Project*, based in Moore, OK, is a non-profit organization designed to create a safe environment for post high school adult children with intellectual disabilities. *The Sparrow Project* provides services and activities to adult children living in the Moore, Norman, and Southwest Oklahoma City areas. The organization was intentionally selected due to their location and number of families served. The parents serve as an unofficial support group to each other due to their connection with *The Sparrow Project.* Prior to the face-

to-face interviews, a pilot interview was conducted with the director of *The Sparrow Project*, and relevant feedback was integrated into the official research process. The pilot participant has an intellectually disabled adult-child living in the home. The interview questions and research structure were approved by IRB, and the principle investigator attended one of the organizations structured meetings. The principle investigator verbally presented the purpose of the research and requested voluntary participation from the caregivers (O'Leary, 2017). Following the meeting, the director of *The Sparrow Project*, on the behalf of the principle investigator, sent an email request to the caregivers that have adult children with intellectual disabilities participating in *The Sparrow Project* program and events.

Participants

   The Sparrow Project averages 40 active members, most are adult children with intellectual disabilities that have aged out of the public-school system. A total of 12 caregivers responded with an interest to participate in the research. All 12 were then contacted through email by the principle investigator to schedule an in-person interview. Eight of the 12 contacted actually participated in an in-person interview; two fathers and six mothers. Two of the 12 were unable to accommodate an in-person interview. One, of the 12, never responded to the investigators email(s). All the interviewed caregivers are parents of children with intellectually disabilities.

   The study's research goal was to complete approximately 40 interviews for the study. A larger data set would have allowed for a non-parametric or parametric correlation analysis for enhance understanding and compare the living environment conditions with current Universal Design principles. The usefulness would allow researchers to inform future policy and design making decision to be reached. Intellectual disabilities impact a broad spectrum of the

population, and the principle investigator wanted to avoid unintended bias related to living

conditions or assumed economic status related to geographic neighborhood location(s);

therefore, the initial interviews were conducted at neutral sites, such as a school library or a local

coffee shop. The interviews were recorded and reviewed privately by the principle investigator,

and the data was coded with data key kept separate and secure. A few in-home visitations were

originally intended to be a secondary aspect of the study. The in-home visits would have

provided a visual understanding of design choices implemented and the ability to recommend

other design modifications. However, the stay safer at home order from local government(s) due

to the Covid-19 pandemic was prohibitive of in-home visitations. Several of the children

experience compromised immune systems related to their disability and were considered high

risk of contracting the virus.

Data Collection

Information that was gained from the interviews include the following structured

(questions one to four) and open-ended (questions five to eight): 1) The diagnosis/classification

of Intellectual Disability, 2) The gender of the dependent adult, 3) The actual age of the

dependent adult vs. IQ age, 4) Does the dependent adult live with a care giver? If yes, what is

the relationship to the dependent adult? I.E. parent, other family member or third party? 5)

What challenges or obstacles have you had to overcome within your home? 6) What area of the

home is the most challenging? 7) How have needs changed as the dependent adult has aged?

And 8) What modifications have been made to your home, or what modifications do you wish

you could make to your home.

Data Analysis

Since the data set was small, consisting of 8 voluntary participants, the analysis was kept to a manual coding process. The study used the Emergent Design research model that allowed the interviewer to learn from the caregiver's unique experiences (Creswell & Creswell, 2018). Once the data was collected, it was reduced and sorted into themes using Braun and Clarke's (2006) *6 Steps of Thematic Analysis*. The first step involved reviewing the data collected from each participant to include transcribing audio recordings. Once the principle investigator was familiar with the data collected, the initial coding process was implemented. The participants data was manually entered into a spread sheet, and each participant was assigned a number by the principle investigator to protect the participants identity and privacy. The process of manual coding utilized highlighters to color code and identify similar words or repetitive themes. Mind mapping on a dry erase board was then used to cluster the identified codes into more concise themes. The coding process resulted in three primary themes: 1) safety, 2) normalcy and 3) independence. Since each family environment is unique, it was important to identify similarities, as well as differences.

Limitations

While there are no known risks attached to the study, a consent form and university contact information was provided to reduce or deal with any sort of risk. The principle investigator recognizes the existence of bias in qualitative research including sample size, selection of participants, procedure, interviewer bias and response bias to name a few. Even though *The Sparrow Project* has approximately 40 members, the principle investigator was only provided contact information for the caregivers that volunteered to participate in the research, mitigating selection bias. Due to the nature of the research, interviewer bias could

subconsciously influence how a participant answers the interview questions. Therefore, the principle investigator conducted each interview using a printed script to maintain consistency between participants. Prior to the current research, the principle investigator had limited information in-regards to the intellectually disabled community. The principle investigator incorporated extensive literature research to expand knowledge relevant to the research. In advance of the actual in-person interviews, the principle investigator emailed each participant a copy of the interview questions along with the consent form. Assuming each participant reviewed in advance, they were provided additional time to think about and formulate their answers without feeling rushed. The primary limitations include the amount of time allowed to schedule and complete interviews, and then compile and analyze the data collected. Additionally, the ability to gain enough voluntary participation in order to have relevant comparable data. Lastly, it was anticipated that the data would be diverse making correlations difficult to make across the data sampling. An unanticipated disruption occurred when Covid-19 became a global pandemic and face to face interviews and home visits could no longer take place.

Universal design solutions are necessary in single-family residential homes. These design solutions will aid dependent children with intellectual disabilities as they age in place. This research will provide a glimpse into the successful family practices between caregivers and adult dependent children. Ongoing research is recommended to gather a broader sampling of data and to generate greater correlations.

In order to protect the identities of the parents and their disabled children, no names will be used. Additionally, the term parent will be used rather than referring to father or mother. Likewise, the term child will be used in place of he or she. Lastly, the behaviors and

environmental examples will not be discussed in direct reference to a specific diagnosis, but

instead under the general term of intellectual disability.

CH 4. RESULTS

Introduction

The study's goal is to identify the following: 1) What design challenges can be withheld in single-family residential homes from the perspective of the primary caregivers of children with intellectual disabilities, and 2) Which of the seven Principles of Universal Design aid the growing population of multi-generational families living with children with intellectual disabilities? The study consisted of eight caregivers participating in face-to-face interviews. Presented in this chapter are the demographics and information collected during the interviews.

Demographics

All of the caregivers interviewed are parents of children with ID living at home. The eight parents interviewed represent 10 children with ID, five females and five males, shown in table 1. Two of the caregivers have multiple dependent children with ID living at home. Two of the children are still classified as minors under the age of 18. The remaining eight children range in age from 22 to 38 years of age, and the average age being 27.

Table 1: Demographic Profiles

Demographic Profiles

Demographic Characteristics	Frequency
Caregiver	
Mother	6
Father	2
Dependent Gender	
Male	5
Female	5
Dependent Age	
Under 18	2
19-29	7
30-39	1

Half of the dependents have either Down Syndrome (3), or Autism (2). The other half vary: Epileptic Encephalopathy to include seizures and low IQ (1), Seizure disorder including delayed fine motor skills and intellectual delay (1), Cognitive Intellectual Disability - Minus chromosome 8 (1) and Vanishing White Matter (VWM) (2), shown in table 2.

Table 2: Intellectual Disabilities represented

Intellectual Disabilities represented

Diagnosis	Frequency
ID	
Down syndrome	3
Autism	2
Vanishing White Matter	2
Epileptic Encephalopathy	1
Seizure disorder	1
Cognitive ID minus chrom 8	1

All but one parent stated they had made either structural modifications, Furniture Fixture and Equipment (FF&E) changes, or both within their existing home, shown in table 3.

Table 3: Home modifications

Home Modifications

Type of Modifications	Frequency
Modifications	
Yes	7
No	1
Modification type	
FF&E	7
Structural	3/7
None	1
Rooms Modified	
Bathroom	3/7
Kitchen	7
None	1

The structural changes included adding a bonus room, a second story, and widening hallways and doorways. The FF&E modifications included replacing tubs with walk in showers, adding temperature sensor faucets, installing a lower height toilet, and replacing a small builders grade tub with a larger porcelain tub. Accessibility is the primary reason structural and FF&E modifications were implemented. However, the need to provide privacy and independence, to those with intellectual disabilities, justify many other modifications.

Steps and staircase accessibility

Five of the parents considered steps to be problematic for various reasons. One parent explained their child is fine to go downstairs, but the child does not like going up open stairs without risers. The physical opening causes uncertainty for the child, and for this reason, the parent and child have practiced going in and out of their in-ground storm shelter. In the event of a tornado emergency, all users should be physically and emotionally confident to navigate the

Figure 11: Inground storm shelter stairs

(Huntsville Tornado Shelters 2020)

challenging stairs shown in figure 11. The stairs in an in-ground storm shelter can be difficult for many people, especially the elderly and individuals with mobility impairments.

The stair example(s) could also be further considered by using the seven principles of universal design. As stated above, one could argue that the stairs provided in an in-ground storm shelter do not meet any of the universal design principles:

- 1) Equitable use: A person with mobility issues would likely need assistance.

- 2) Flexible: The design has a single purpose to provide protection during a tornado.

- 3) Simple and intuitive: The stairs required practice.

- 4) Perceptible: Yes, going down, but going up was problematic.

- 5) Tolerance for error: Potential to slip and fall going up or down.

- 6) Low physical effort: A person with mobility issues would likely need assistance.

- 7) Size and space for approach: A person with mobility issues would likely need assistance.

Appropriate universal design applications could improve the person-environment complementary congruence in this situation through the use of a built-in safe room. A built-in safe room also provides protection from high wind weather events such as tornadoes and hurricanes, and the hardened structure is designed to meet the Federal Emergency Management Agency (FEMA) criteria (FEMA, 2020).

- 1) Equitable use: A built-in safe room is the most accessible option for persons of all abilities, as well as family pets.

- 2) Flexible use: The built-in safe room can be camouflaged using interior finishes that provide a dual function within the home, such as a closet shown in figure 12.

- 3) Simple and intuitive: Closet accessibility and use is typically a behavior learned through repetition as a function of daily life.

- 4) Perceptible: Closet accessibility and use is typically a behavior learned through repetition as a function of daily life.

- 5) Tolerance for error: The elimination of stairs provides a safer transition.

- 6) Low physical effort: A person with mobility issues could access independently or with minimal aid.

- 7) Size and space for approach: A wider door opening accommodates a walker or wheelchair.

Figure 12: Saferoom designed as a closet

(Acorn Fine Homes, 2020)

Storm shelters and saferooms are optional features for residential homes, and both options can be retrofitted to an existing home. According to www.fema.gov, the construction cost of a safe room in an existing home is about 20 percent higher than in new construction. Storm shelters or saferooms are not required by code including in geographic areas prone to tornadic weather such as Oklahoma.

In contrast to those parents not wanting a home with too many stairs, one parent felt a two-story home would provide privacy and independence for their adult children with intellectual disabilities. The ideal home describe by this parent would have living and entertaining spaces, including a kitchenette on the second floor. The space would also be accessible by a front or main staircase, and there would be a back or secondary staircase. The primary reasoning for two staircases was to provide an alternate egress in the event of a home fire. An additional benefit of a secondary staircase allows users to access a specific portion of the home, usually the kitchen, in a more private manor without walking through the primary living area of the home. It should be noted that this family has been looking for such a home, and as of this interview the search had been unsuccessful. The parent also stated that they did not want to build a custom home, but they would consider some modifications if a home met most of their requirements.

Finish materials on stairs is an important consideration to reduce an accidental slip and fall. One parent mentioned wanting wood flooring because it was prettier and easier to keep clean but opted to keep carpet for safety.

One parent pointed out that it is very difficult to find a new or existing home that has at least one zero threshold entry point into the home. It is common for front doors to have at least one step from the sidewalk to the porch area, and garages also have a standard step up at the door

passage into the home. If a home does have an entry with a zero threshold, it is likely a side door or a back door that does not have sidewalk accessibility.

Accessible doors and hallways:

In addition to cognitive and developmental delays, two of the children also required the assistance of specialized wheelchairs for mobility. The specialized design makes the mobile devices even more difficult to maneuver in tight spaces, including those that meet accessibility standards. The modern wheelchair designs need 42 to 48-inch openings to maneuver with ease.

Routines and adaptive behavior examples:

The proximity of the master bedroom in relation to the child's bedroom was problematic for one parent. The parent felt the rooms were too far apart prohibiting the parent from hearing the child should the child have a seizure and need assistance. For reasons unknown, the parent had not considered the use of assistive video technology such as a baby monitor. Instead, the parent admitted to sleeping in the living room which was closer in proximity to the child's room and allowed the parent to hear better and respond quicker to the child in the event of an emergency.

Another parent explained that their child had low muscle tone and a weak grip, characteristics common to the intellectual disability diagnosis. To avoid the child dropping and breaking items such as dinnerware, the parent chooses to carry the items for the child. Additional details would be necessary to provide a plausible solution that would aid in providing the child with additional independence. One possibility would be the use of lightweight dinnerware such as melamine known for its durability and readily available online and at home goods retailers.

One of the children was described as routine oriented. Each evening the child prepares a lunch kit to take to work the next day. The contents are precisely laid out on the kitchen counter rendering the space unusable until the lunch is packed, and the child has gone to work the next day. In a small kitchen with limited flat surface, this could be problematic for other members in the household should they also need to use that space.

In more than one household, the children's bedrooms were described as multi-functional and furnished to support a variety of activities beyond sleeping and personal care. There was dedicated space for living/lounging and entertainment such as electronic gaming, watching TV/movies, playing with toys, board games, and putting together puzzles.

All of the parents interviewed did have one thing in common, they wanted to provide as many options that supported independence for their child/children, at whatever stage they were at intellectually. These choices included being able to select coordinating outfits and dress themselves, accessibility to food/snacks and food prep (microwave use) or induction cook tops, cleaning and organizing, front load washer and dryers. Personal hygiene – shaving. Freedom of space to isolate or to socialize with friends. For those that were physically limited, the ability to maneuver without barriers.

Parents are told one thing about life expectancy, but when the children live longer it changes decision making and standardization in residential homes could help minimize modifications. Everything gets harder as they get bigger and cannot do things for themselves.

When making specialized design modifications to a single-family residential home, a common cause for concern is the possible negative impact on future resale of the home. Resale is an important consideration; thereby, creating the opportunity for builders and designers to collaborate with the occupants, and provide design solutions that integrate with the principles of

universal design. One parent had stated that a walk-in shower would be preferred over a tub-shower combination but decided not to invest in the remodel due to resale.

Several of the interview participants actually used the words independence, normalcy and safety to describe various situations or to explain their reasoning when making adaptations within the residential home. Through the coding process and the data analysis, the repetitive verbiage evolved into three common themes among the caregivers: 1) keeping the individual safe, 2) maintaining a sense of normalcy and 3) providing an appropriate level of independence or autonomy.

CH 5. DISCUSSION

The current research is centered around the concept of person-environment complementary congruence between the family unit and the single-family residential home. The study's origin began with an interest to gain knowledge about the growing population with intellectual disabilities, and then determine which if any universal design principles could aid such individuals within the residential home. The design challenges identified through the data analysis were clustered into three themes: safety, normalcy and independence. The seven principles of universal design were applied to each of the themes to determine relevance and practical application. The principle investigator identified a direct correlation between the two constructs and concluded that all seven principles contribute to the safety, normalcy and independence of individuals shown in figure 13.

Figure 13: Connecting themes to UD principles
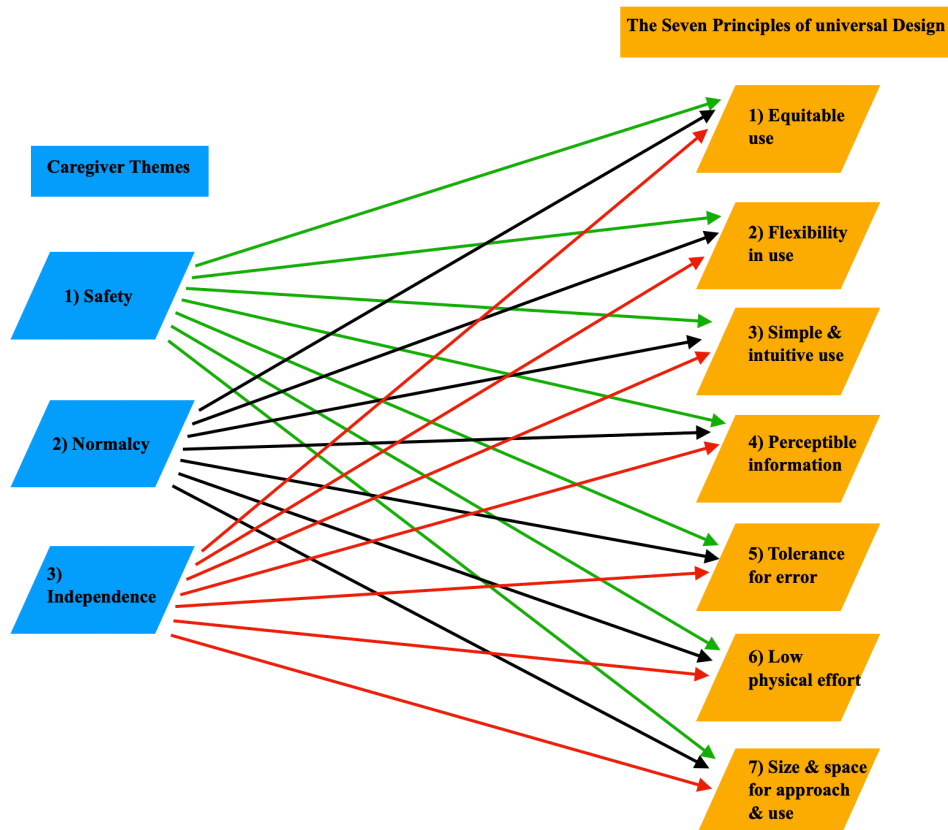
Safety

A safe environment is purposely designed to protect all of its users from unintentional harm. The individual logic associated with the seven principles of universal design can be directly applied to an environment to enhance safety and protect all of its users.

Normalcy

Handicap or accessible hotel rooms are not typically viewed as normal by a non-disabled user. Similarly, the participants in this study prefer not to live in a home with institutionally recognized accessible fixtures and equipment. Further supporting Mace's concept of universal as an approach to designing products and the built environment to be aesthetic and usable to the greatest extent possible, regardless of the users age, ability, or status in life (Jones, 2010; Mace, 2008).

Independence

Independence applies to both the caregivers and the children with intellectual disabilities. As the children continue to advance and develop with age, it is important that the living environment supports an appropriate level of independence. Closet and storage organization promote the ability for a child to easily make clothing or movie selections without the aid of a caregiver. When a child is able to perform simple tasks, the caregiver is then free to focus on performing other duties.

The Seven Principles of Universal Design

1) Equitable use:

One key learning gained from both the literature and the participants is the importance of providing design options for the entire family of users. The research primarily focused on the specific needs of the intellectually disabled from the caregiver's perspective.

2) Flexibility in use:

Even though the number of participants was limited, they represented the complexity of the intellectually disabled community. The primary variables across all intellectual disabilities include the range of diagnosis, and the level of physical and cognitive functioning per individual. These two variables alone challenge the concept of designing for all. While some similarities did exist, this information should not be generalized by designers or architects. Instead, the research supports those in professional practice to adopt inclusive design research methods that build upon existing knowledge.

3) Simple and intuitive use:

A design feature that is simple and intuitive is more likely to be utilized by a child with an intellectual disability. Nearly all of the participants kids have a daily routine that involves the use of electronic devices such as tablets and gaming devices. Ironically, electronic devices are not always considered simple and intuitive to older users with full cognitive abilities.

4) Perceptible information:

The addition of temperature sensor faucets provides a visual understanding between hot and cold. While it is predominately a safety feature to prevent unintended scalding, knowing the difference also promotes confidence in use that encourages independent behavior choices.

5) Tolerance for error:

The participants wanted options that would keep the intellectually disabled safe from harm, but they did not want the look and feel of an institutional environment. They wanted the home to look and feel normal, a key component of universal design.

6) Low physical effort:

A modification that has become more commonly specified throughout residential construction is the use of lever handles on doors and facets. A lever handle requires less force to operate, and the handle can be manipulated by applying pressure with the side of a hand or with an elbow. A lever handle does not require gripping or twisting which is often difficult for people suffering with arthritis or an injury. The lever handle design choice also benefits anyone who has their hands full, i.e. groceries, laundry, or a baby (Jones, 2010).

7) Size and space for approach and use:

Universal design has been more readily adopted within commercial design settings; however, some successful practices are starting to merge into the residential sector. Builders and interior designers are slowing implementing thirty-two-inch wide door openings in new construction homes, but this feature can be cost prohibitive in spec homes; and therefore, often limited only to those that can afford a custom-built home. Changing the width of door openings is a simple adjustment that would benefit people who use wheelchairs, walkers or crutches. Additionally, the wider door openings make it easier to move furniture, suitcases or a baby stroller through the door, and they provide easier access for people who are obese (Jones, 2010).

From the point of view of a practicing professional, home builders continue to make conservative design choices that meet minimum code requirements, resulting in antiquated residential home designs that fail to address basic accessibility or the growing needs of multi-generational families. One such example is the curbless or zero-threshold shower entry that has gained popularity in many new construction homes. The flat floor surface allows for walker and wheelchair accessibility, and the design feature eliminates a potential trip hazard (tolerance for error). Unfortunately, the shower entry openings typically meet the minimum required width of

30 inches which then negates the accessibility. The curbless shower opening shown in figure 14

only measures 25inches in a new construction home built in 2018. By making the entry 32 to 36

Figure 14: Curbless shower entry with 25 inch opening

(Huff 2020)
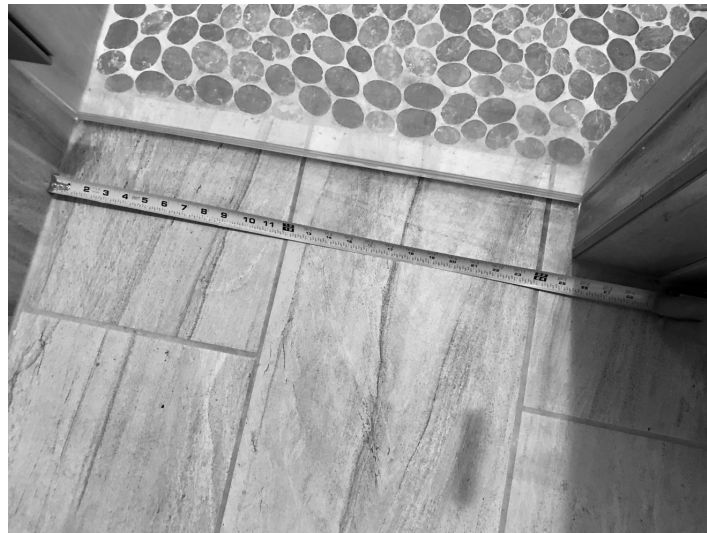
inches, it would meet ADA standards and appeal to a broader group of users, a key component of

universal design. Design results are still too generic for aging in place, and they do not address

the specific needs of the ID population.

Advanced materials and modern technology are under-utilized by builders, designers, and

homeowners. The absence of UD solutions within the residential community is robbing

individuals of independence and quality of life.

Through the research process, the researcher believes that it is time to move past

conservative design practices within single family homes, and the current ADA standards need to

be expanded into residential design to better serve the needs of multi-generational families aging

in place in single-family residential homes.

Future Research

Due to the limited number of participants and the variety of intellectual disabilities represented in the study, the results of the study cannot be generalized, and the design recommendations for consideration may be unique to the individual's environment or circumstance. While the study's sample size is small, the investigative process and consideration would be viable and contributing for future inclusive design research and policy administration.

In-home observations

The current research primarily focused on the specific needs of the intellectually disabled from the caregiver's perspective. As the study evolved, it became more apparent that the study would have benefited from observations within the family home. Ideally, the observations would include the entire family unit to understand the dynamics of a multi-generational home. A sampling of in-home visitations was intended to be a secondary aspect of the study. The in-home visits would have provided the researcher with visual evidence related to the design choices implemented by the caregivers. Additionally, the in-home visits would have provided the researcher the opportunity to recommend design modifications beneficial to the family unit. The impact of the Covid-19 global pandemic prohibited such in-person interactions due to the stay "safer-at-home" order from local government(s). Several of the children experience compromised immune systems related to their disability and were considered high risk of contracting the virus. Upon reflection, the use of technology such as FaceTime or ZOOM could have provided a virtual insight into the spatial use and possible challenges within the homes.

During the Stay-at-home order, the researcher followed up with each of the participants. All of the participants expressed that their children were experiencing confusion and difficulty understanding why their routines and activities had been disrupted. Knowing that this group of

individuals had a very active social calendar, the circumstances of daily isolation made the research wonder if the home environment contributed positively or negatively to the family unit (person-environment congruence). Covid-19 will likely spawn endless research ideas.

Family unit

The exact make-up and size of each family unit is also unknown in this study. Some of the participants were more forthright in discussing the size of the home, who lives in the home, and how these factors might impact design modification decisions. Family demographics combined with the spatial allocations within the home would expand the research to be more inclusive of designing for the family unit rather than an individual.

Economic data collection

Economic data was not collected as part of the study; however, it was apparent during the interviews that families with greater financial resources had invested in modifications to their home or were planning to make future investments in modifications. Collecting economic data in the form of home value could provide additional insight into the frequency in which universal design modifications are implemented.

Age of home

The results of the interviews revealed a disparity in the age of each home. The cost and scope of a renovation project can be adversely impacted in older homes due to changes in residential building code standards. It is important to homeowners to maintain a marketable home value while making renovations to an older home. Several of the participants admitted to not making modifications that might negatively impact the future resale of their home. It is important for an architect or designer to know the year a home was built prior to recommending universal design modifications.

Conclusion

In order to overcome the disparity in inclusion, there needs to be a shift in perception among builders and designers. Instead of viewing a disability as an obstacle, the disability should be considered an opportunity to expand knowledge and creativity within the design process. According to architect, Dan Bucsescu, "The ultimate goal of design is to create unique memorable places, site-specific and time-appropriate, as well as functional places that are comprehensible and legible" (Bucsescu & Eng, 2018). Universal is a broad term that best describes this ideology of designing for all, but not without limitations. In reality, designing for all can be cost prohibitive. Regardless, we can learn how accessible design has helped those without disabilities, how technology has advanced design options, and how other industries are adopting the concept of universal design. When universal design is properly applied it is aesthetically pleasing, it anticipates future needs, and it supports independent living for the aging population including those with intellectual disabilities. Universal design is not perfection, but it is an ever-changing attempt to improve quality of life through equality and inclusion. A design without inclusion will likely fall short, despite the designer/architects perceived understanding of universal design.

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Appendix A

IRB consent form

Signed Consent to Participate in Research

Would you like to be involved in research at the University of Oklahoma?

I am Denise Huff from the Interior Design Department and I invite you to participate in my research project entitled Universal Design and Intellectual Disabilities. This research is being conducted at a neutral site (public library, coffee shop, etc). You were selected as a possible participant because you are a care giver to a dependent adult with an intellectual disability. You must be at least 18 years of age to participate in this study.

<u>**Please read this document and contact me to ask any questions that you may have BEFORE agreeing to take part in my research.**</u>

What is the purpose of this research? The purpose of this research is to learn from the care givers of dependent adults with intellectual disabilities. Because many dependent adults are now living past the age of 50, there is a strong likelihood many will outlive their primary caregivers. As a result, alternative housing such as institutional care is becoming a necessary option for both the caregivers and those receiving care. Research is necessary to create appropriate housing that will encompass successful transitions from the home to the institution; while maintaining the security, comfort and familiarity experienced within the family home. As dependent adults age and outlive their caregivers, it is important to understand the factors and influences that have positively and negatively affected their development and overall quality of life. This information will be used to recommend care options that will support a successful transition of care from one environment (predominately single family residential) to another (supervised small group housing).

How many participants will be in this research? Up to 40 people will take part in this research.

What will I be asked to do? If you agree to be in this research, you will participate in a semi-structured interview, a small sampling of the participants will then be requested to gather additional information within the home on a voluntary basis.

How long will this take? Your participation will take approximately 1 to 2 hours.

What are the risks and/or benefits if I participate? There are no risks and no benefits from being in this research.

Will I be compensated for participating? You will not be reimbursed for your time and participation in this research

Who will see my information? In research reports, there will be no information that will make it possible to identify you without your permission. Research records will be stored securely and only approved researchers and the OU Institutional Review Board will have access to the records.

You have the right to access the research data that has been collected about you as a part of this research. However, you may not have access to this information until the entire research has completely finished and you consent to this temporary restriction.

Do I have to participate? No. If you do not participate, you will not be penalized or lose benefits or services unrelated to the research. If you decide to participate, you don't have to answer any question and can stop participating at any time.

Will my identity be anonymous or confidential? Your name will not be retained or linked with your responses <u>unless you specifically agree</u> to be identified. Please check all of the options that you agree to:

I agree for data records to include my identifiable information. ___Yes ___ No

I agree to being quoted directly.___ Yes ___   No

I agree to have my name reported with quoted material.___Yes ___No

I agree for the researcher to use my identifiable data in future studies.___Yes ___   No

What will happen to my data in the future?

We will not share your data or use it in future research projects.

Audio Recording of Research Activities To assist with accurate recording of your responses, interviews may be recorded on an audio recording device. You have the right to refuse to allow such recording without penalty.

I consent to audio recording.   ___Yes ___ No

Photographing of Research Participants/Activities In order to preserve an image related to the research, photographs may be taken of participants. You have the right to refuse to allow photographs to be taken without penalty. Please select one of the following options:

I consent to photographs.   ___ Yes   ___ No

Your photographs or video images may be used in University research reports unless you tell me not to do this.

Will I be contacted again? The researcher might like to contact you to gather additional data or recruit you into new research.

I give my permission for the researcher to contact me in the future. ___Yes ___   No

Who do I contact with questions, concerns or complaints? If you have questions, concerns or complaints about the research or have experienced a research-related injury, contact me at (405) 308-2611 or <u>denise.e.huff-1@ou.edu</u>, or Dr. Natalie Ellis at (573) 289-1739 or nellis@ou.edu.

You can also contact the University of Oklahoma – Norman Campus Institutional Review Board (OU-NC IRB) at 405-325-8110 or <u>irb@ou.edu</u> if you have questions about your rights as a research participant, concerns, or complaints about the research and wish to talk to someone other than the researcher(s) or if you cannot reach the

researcher(s).

You will be given a copy of this document for your records. By providing information to the researcher(s), I am agreeing to participate in this research*.*

Participant Signature	Print Name	Date
Signature of Researcher Obtaining Consent	Print Name	Date
Signature of Witness (if applicable)	Print Name	Date

Appendix B

Introduction statement

Hello! My name is Denise Huff, and I am a graduate student at the University of Oklahoma studying interior design. I am requesting your participation in my research project linking residential design and Intellectual Disabilities. You were selected as a possible participant because you are a caregiver to a dependent adult with intellectual disabilities.

Appendix C

Interview questions

1. What is the diagnosis/classification of Intellectual Disability?

2. What is the Gender of the dependent adult?

3. What is the actual age of the dependent adult vs. IQ age?

4. Does the dependent adult live with a care giver? If yes, what is the relationship to the dependent adult? i.e. parent, other family member or third party?

5. What challenges or obstacles have you had to overcome within your home?

6. What area of the home is the most challenging?

7. How have needs changed as the dependent adult has aged?

8. What modifications have been made to your home, or what modifications do you wish you could make to your home?