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Metamorphosis Towards Independence: Experiences with Developmental Disabilities in

Smart Home Living

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Abstract

Due to recent technological advances, smart homes are continuing to gain support as a safe, autonomous living option for adults with developmental disabilities (DD). Limited research has documented residents' perceptions of assistive technology (AT) or personal satisfaction within smart homes. This qualitative study explored the lived experiences and quality of life (QoL) among adults with DD after living one year in a smart home. Stakeholders from all perspectives (residents, parents, and caregivers) provided their personal feedback through individual interviews, and residents participated in an additional focus group for data collection. The data yielded five themes: *Life is easier with smart components; Spreading their wings within the community; Navigating roommate boundaries; Metamorphosis towards independent adults; and Understanding what independence really means.* The themes reflect substantial growth, when compared to two prior studies of this population, from planning and then moving into the smart home. Researchers shared anticipation for future growth.

Keywords: developmental disabilities/intellectual disabilities, smart homes, assistive technology, supported living, quality of life

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Adults with DD have limited residential living options due to a lack of resources. In one midwestern state, approximately five percent of adults with DD lived by themselves without guidance or supervision (ANCHOR & UCP, ©2020). In 2020 Siddiqi reported that rising healthcare costs, staff shortages, and a rising number of people needing services contributed to increasingly limited housing options. As of 2016, living options for adults with DD did not provide individuals access to flexible supports to enhance their abilities to practice independence (Leach, 2016). The current research study focused on understanding residents' perspectives on using AT and the social supports in place in a newly built smart home in the Midwest. Studying the residents' experiences benefited adults with DD as a demonstration of the effectiveness of living in a smart home as a potential long-term living option.

Statement of the Problem

The challenges in complex cognitive reasoning experienced by many adults with DD have reduced the ability of these individuals to independently participate in community-based occupational and social pursuits. Adults with DD also experienced limited activity choices, restricted reimbursement for caregiver services, and a shortage of independent living options (Burke et al., 2020; Leach, 2016). However, the growing area of AT has increased resident self-determination and independence, leading to a decreased need for direct staffing hours. (Smith et al., 2020). Yet, more research is needed on the effectiveness of AT in order to validate support for the prior findings of improvement in quality of life (QoL) and promotion of autonomy for adults with DD.

Purpose

The purpose of this study was to qualitatively discover the lived experiences of the residents' satisfaction and participation in a Midwestern based smart home. The lived experiences explored were changes in the participants' satisfaction or self-perceived QoL from fall 2020 to fall 2021. Furthermore, the researchers were interested in the residents' perceptions of the contribution and effectiveness of AT to increase their sense of autonomy and occupational participation.

Rationale

The number of children diagnosed with DD rose significantly in recent years, which increased the need for living arrangements for individuals with DD as they became adults (Zablotsky, 2019). The intention of this study was to provide data on the lived experiences of residents, parents, and caregivers of adults with DD who with the assistance of AT, can participate in their daily occupations safely with less reliance on direct-care staff.

Query

The research query was: From the residents' perspective, what aspects of the smart home contributed to their satisfaction with these living arrangements? Answers to queries from prior research were also collected. Prior queries were: "What are the experiences of the residents … and their key stakeholders in their current home and what are their hopes and fears for their new housing" (Kennedy et al., 2020), as well as "What are the lived experiences of the smart home residents in terms of safety, supported living, and QoL?" (Albers & Schott, 2021). The final query was: "How do the residents' experiences of living in the smart home compare and contrast to the original qualitative data collected by the researchers of the pre-study?".

Scope

Researchers interviewed residents, residents' parents, and the facility staff (caregivers) to understand how the smart home influenced the residents' abilities to become more independent, as well as how their independence journey has progressed over the past three years. The semi-structured interviews and focus group lasted up to an hour and a half, either in person or via Zoom dependent upon the participant's role and their preferences.

Assumptions

The researchers assumed that the residents had become familiar with the smart home over the course of the previous year. Researchers expected the COVID-19 pandemic restrictions would have been lifted, permitting in-person interviews when preferred. The planned alternative was for interviews to be conducted virtually. Researchers presumed that participants provided truthful, insightful responses to the interview questions, regardless of the interviewer's presence. The researchers also assumed that the participants' preferred mode of communication was effective in conveying their intended message and was accessible during the interviews.

Operational Definition of Terms

The smart home was defined as a technology-equipped, pilot house that allowed adults with DD to become more autonomous in a safe manner (Siddiqi, 2020). Autonomy was the individual's ability to choose and complete everyday activities within the home and community while using remote caregiver support as needed (Siddiqi, 2020). Developmental disabilities (DD) were disorders of the central nervous system that delay a child's ability to accomplish milestones across more than one developmental area, resulting in life-long physical and/or cognitive impairment(s) that impact(s) one's performance in daily tasks (Center for Disease Control and Prevention, 2020; Reiss, 2009). Assistive technology (AT) included adaptive home appliances,

interactive devices, wearable electronics, and other smart technology that allowed residents to safely live on their own with remote caregiver support (Siddiqi, 2020). Quality of Life (QoL) was a subjective measure as to how residents feel, specifically for this research study focused on how the smart home components allowed them to live more independently, comfortably aligned with their personal values, contextual standards, and life satisfaction (adapted from the American Occupational Therapy Association (2020) and World Health Organization (2021)).

Literature Review

This literature reviewed the impact of AT, encouragement of occupational participation, and supported living for adults with DD. AT decreased the task demands on users and their caregivers through opportunities for individuals with DD to accomplish occupational activities with limited physical supervision. There was, however, a gap in the literature on AT supporting autonomy for adults with DD. The Midwestern organization that supported the housing model in this study helped close the gap when they established a smart home living arrangement for adults with DD.

Assistive Technology

Several studies examined the effectiveness of AT to assist adults with disabilities and encourage independence in a smart home setting. In a study of 59 adults (median age 58 years) with physical disabilities and average intelligence, Opecek et al. (2013) found the majority of their smart home residents in Slovenia only used one or two ATs in the home. Researchers theorized that the lack of compliance to prescribed AT was due to either the AT not matching the client's skill set or the ineffectiveness of the technology itself (Ocepek, 2013). Meanwhile, in Levasseur et al.'s (2016) study, 10 adult smart home residents (median age 53 years) with cognitive impairments derived from acquired brain injuries depended on their AT to meet

personal care, transportation, home management, interpersonal relationships, and leisure needs. In a study of 15 individuals with DD (mean age 54) and their care providers in a group setting, the AT implemented was found to be highly dependent on the caregiver's knowledge and initiation to assist the resident in obtaining the technology (Boot et al., 2018). Family members and caregivers also expected the AT to be simple to use and user-friendly to all cohabitants by being reliable and helping to decrease the need for full-time direct supervision (Granbom, 2017; Fange, 2019). To increase proper use and acceptance of technology, Brandt, et al. found client-focused in-person training and support for AT improved their use and acceptance of the technology (Brandt, et al., 2020). When working with cognitively impaired adults, it was also important for the family and caregivers to feel confident about the privacy protections for the users of AT implemented in the home (Brand et al., 2019).

Maich et al. (2019), found there were varied levels of success with AT due to technology issues, overall feelings about technology, and adjustments for a just-right challenge. If AT was not properly matched with an individual's needs, then it interfered with performance (Maich et al., 2019). However, clients experienced an increase in satisfaction with their occupational performance when appropriate AT was accessible (Ocepek, 2013).

Autonomy and Safety

In addition to improved task performance, AT has promoted self-determination by teaching individuals the skills to adapt to environmental and activity-based challenges (Cullen et al., 2017; Panerai et al., 2018). AT provided opportunities for individuals with DD to increase their autonomy as required direct-care assistance declined during performance of Activities of Daily Living (ADLs) with the use of remote monitoring systems to ensure safety (Wagner et al., 2019). In a study of individuals with intellectual disabilities (ID), AT assisted participants with

completing ADL tasks through cueing (Golisz et al., 2018). Söderström et al. (2019) further

determined that self-determination was promoted when individuals with DD were able to initiate

what they wanted to do and expressed such through AT communication devices (Golisz et al.,

2018). Several case studies found the consistent use of video-modeling successfully replaced

caregiver prompting for safe task performance by individuals with ID/DD (Allen et al., 2015;

Golisz et al., 2018). Smith et al. (2016) confirmed video prompted performance provided the

correct level of support for individuals with ID to complete tasks with increased autonomy. In

addition, Dunn and colleagues (2016) found that individuals with DD used iPads to increase their

independence in daily living by self-prompting their learning during job tasks.

   The importance of increasing independence for individuals with DD was also highly

valued to the family members and caregivers, who frequently experienced high levels of stress

and fear due to the time-consuming direct supervision for these individuals (Resta et al., 2021).

Zwierenberg et al. (2019) found that familial caregivers often felt pressured to keep their loved

ones at home leading to burnout and caregiver burden. However, these demands were decreased

through the assistance of remote monitoring services and AT. Similarly, other researchers agree

that telemonitoring and remote services have decreased caregiver demand. Nambisan et al.

(2014) found that remote supervision of high-functioning adults with DD allowed for increased

independence for the individuals, as well as more control for the caregivers. Additionally, Tekola

et al. (2021) found that caregivers of children with DD gained an understanding of the

importance of occupational balance and decreased stress levels through the use of caregiver

training. These telemonitoring services have also been found to lower the overall cost for service

providers (Gentry et al. 2020). Additionally, Stokke et al., (2021) found that the use of telecare

increased safety for patients with multiple disabilities in their homes through remote services to

several individuals simultaneously. Similarly, remote monitoring for aging adults decreased their

fall risk, increased their independence, and enhanced their perceived safety during daily task

completion (Arthanat et al., 2020). Tassé et al. (2020) found that, in addition to feeling safer at

home, individuals with remote caregivers also had an increased sense of privacy.

Encouraging Occupational Participation

For individuals with DD, autonomous actions for increased occupational performance

were prompted by various technologies. Systems such as smart home ecosystems supported

communication protocols among smart home residents (Novario et. al, 2021; Smith et al., 2021),

and provided leisure opportunities such as listening to music or playing audiobooks (Pradhan et

al., 2018). Examples of these ecosystems included Google Home and Alexa, which also

enhanced social participation after practice with electronic communication devices (Smith et al.,

2020; Smith et al., 2021) and retrieved information from the internet for definitions or

work/appointment reminders (Noda, 2018; Pradhan, 2018; Smith et al., 2021) in a friendly

manner (Ramadan et al., 2020; Smith et al., 2020). These devices provided simple, voice-

activated, environmental controls for electronics, such as TVs, lights, door locks, and air

temperature settings (Noda, 2018; Ramadan et al., 2020; Smith et al., 2020). Furthermore, these

systems promoted ADL independence after connecting to smart showerheads, automatic soap

dispensers, bidets, and toothpaste dispensers (Novario et al, 2021). Ultimately, utilizing these AT

features could motivate adult residents to create, and eventually meet goals based on increased

autonomy (Taylor et al., 2019; Satterfield et al., 2021).

Although AT supported autonomy, Wong et al. (2017) found that individuals with DD

were quite overwhelmed when acclimating to new technologies, which emphasized the

importance of simple AT recommendations when available versus complex ones. Smartphones

were relatively simple portable devices (especially for those with visual and cognitive disabilities) (Wong et al., 2017) for social engagement, appointment reminders, cues for routine tasks, and communication during emergency situations (Easley et al, 2017; O'Neill et al., 2020), which all promote autonomy in health management and daily tasks (Wilson et al, 2018). There are also several smartphone apps that allow users to further initiate participation in medication management alongside the oversight of a caregiver or pre-sorted medication machine (Salgado et al, 2018).

Supported Living

Interest in long-term, independent living options for adults with DD (Isaacson et al., 2014; Leach, 2016), as well as supported living options for aging individuals with ID/DD (Spassiani et al., 2019), have risen in recent years. Several types of optimal housing for these populations were described in Leach's (2016) study, such as clustered or dispersed housing (including group homes and supported living facilities). However, Leach (2016), along with Bigby et al. (2017) and Ioanna et al. (2020), have found that supported living fosters the most community engagement, adaptive behaviors, choice, and self-determination skills among the available living options. Moreover, these supported living benefits have resulted in a higher QoL among adults with DD compared to the other options (Bigby et al., 2017; Leach, 2016).

While residents with DD reported increased community and social engagement in supported living, reports of loneliness resulted from no longer living with family members, and failure to make friends in and/or outside of their home setup (Bigby et al., 2017; Isaacson et al., 2014). This was further exacerbated by the high turnover rate of direct service providers (DSPs) in the supported living environment: Ejaz et al. (2015) reported a one-third turnover rate annually. Whereas RahKyung & Dymond (2020) found participation in community activities

was one of the most important aspects of living in supported living residential options. It is

important to consider the downfalls of staff turnover and challenges to development of friends.

Two studies informed means to promote community engagement. A high-quality group home

that already prioritized social inclusion and self-determination was successful (Shipton and

Lashewicz, (2017). Dinora et al. (2020) found that sponsored, residential care homes had more

success in participation of their residents with ID/DD in community activities, when compared to

individuals with ID/DD living in larger, congregate settings or their families' homes.

Additionally, residents expressed the need for more choice from supported housing

agencies in determining who they want to live with (according to ability level, age, personalities,

and interests) to promote better living outcomes (Leach, 2016; Reindl et al., 2016; Roos &

Sødenna, 2020). Lastly, some residents experienced limitations in their autonomy as their

families wanted to continue making decisions for them (Fullana, 2020; Issacson et al., 2014;

Leach, 2016; Reindl et al., 2016).

Summary

Individuals with DD have experienced increased autonomy and QoL through the

assistance of AT and remote caregiver services. Remote caregivers gave individuals with DD

needed support in conjunction with reduced feelings of dependency. Best practice for AT

recommendations required a holistic view of the client's needs, client access to information about

the AT, training, and support for use of the technology. These practices increased autonomy and

promoted independence for individuals with DD for the performance of daily occupations.

Research indicated supported living can produce the most desired outcomes for adults with DD

toward increased autonomy and QoL. Researchers in the current study examined the similarities

and differences between the benefits found in the literature to the lived experiences of residents in one Midwestern smart home.

<p style="text-align:center">Methods and Procedures</p>

Research Design

The research design of this study was a qualitative, descriptive case study that examined the lived experiences of four individuals, their parents, and caregivers collected from nine semi-structured interviews and a focus group (see Appendix A), as well as data from interviews and focus groups conducted in studies of the same participants and smart home from the past two years. This study was categorized as a descriptive case study because it investigates one smart home with four residents (Jackson, 2015; Portney et al., 2009). This design was chosen to analyze participants' perspectives in-depth, with the hope of revealing insights that are true to these residents (Jackson, 2015) regarding the use of AT within the smart home.

Sample

The sample of this study included four smart home residents, their parents, and two smart home staff members who participated in a previous study conducted by Albers and Schott (2021). Inclusion criteria for the residents were being eighteen years old (or older), being diagnosed with at least one DD and having resided at the smart home for one year. Residents' parents must be one or both legal guardians, who are available at the same time for one interview. Lastly, inclusion criteria for the Midwestern organization staff involved being a caregiver or house manager that has been employed with the organization's smart home and participated in the previous research study by Albers and Schott (2021). All participant interview guides were written at, or below, the fifth grade reading level to ensure residents understood all questions.

Instrumentation

Necessary resources for this study were four different interview guides (Appendix A); a digital audio-recorder; video teleconferencing software program; computers; HyperRESEARCH software; data storage per research protocol; and a private room to conduct interviews. Student researchers elicited the narratives of participants' lived experiences in the smart home through open-ended questions pertaining to the research queries. As this study is intended to facilitate data analysis between data from current and previous years, the interview guides were adapted from those of the previous study completed by Albers and Schott (2021).

Procedure for Data Collection

The data collection process of this study was adapted from Albers and Schott's (2021) study. After IRB approval was received, clinical tutor and the Midwestern organization liaison, Kate Lopez, invited each participant from Albers and Schott's (2021) study by phone using the recruitment script (Appendix C). During recruitment, Kate Lopez asked the eligible smart home residents and staff to participate face-to-face (following the organization's COVID-19 Pandemic Response Procedures listed in Appendix D), and parents to participate via a video teleconferencing software program.

Next, Kate Lopez determined specific data collection times within September and October 2021. Upon agreement to participate, each resident (or their legal guardian, if applicable) signed the organization's Release of Information Form (see Appendix E) via DocuSign or paper copy. This form ensured that residents agreed to the organization sharing information regarding their age, diagnosis, and education level with the authors, and gave permission for the authors to interview residents' parents.

Each interview began with the informed consent process (see Appendix B) before any questions were asked. After consent was obtained, each interview/focus group was conducted by two researchers and Kate Lopez in a private location. One researcher began with the welcome script (Appendix F) and led the interview while the other researcher recorded field notes and operated the audio recorder. The two researchers and Kate Lopez then conducted the interview/focus group using the semi-structured interview guides listed in Appendix A. After all individual interviews were completed, two researchers and Kate Lopez led a focus group with the smart home residents. The focus group began with a researcher reading a welcome script (see Appendix F), and then asking questions from the focus group interview guide (see Appendix A).

To increase the dependability of this study, an audit trail was maintained to document all data analysis decisions (Connelly, 2016). The audit trail included ongoing documentation of code-recode procedures that recorded common themes found within the transcriptions and observation notes (Stahl & King, 2020). During the iterative code-recode processes, researchers were triangulated at the initial transcription level, at the code level, and during the thematic analysis. Researchers then collaboratively synthesized the most common, pertinent results found, increasing the study's credibility (Stahl & King, 2020). While these strategies enhanced the validity and reliability of the study, it is important to recognize the lack of generalizability of this study towards other smart homes for adults with DD, since this research utilized a case study design (Leung, 2015).
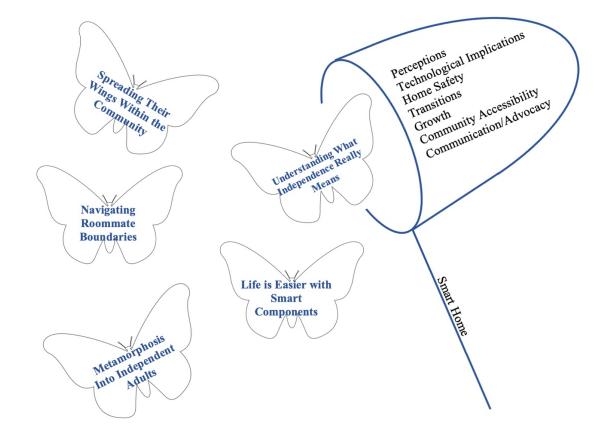
Data Analysis

Researchers transcribed the recordings of the interviews and focus group verbatim using a word-processing software. One researcher played the recording in a secure setting and another researcher checked that no details were left out of the transcription to ensure inter-rater data

reliability. The interviews and focus group were transcribed and each researcher coded every interview and the focus group. After reading the full transcripts at least twice, each researcher determined their codes and operational definitions. Through peer debriefings, the four researchers reached a consensus on the codes and operational definitions and re-coded all transcripts with the triangulated codes. HyperRESEARCH was used to compile the data for the researchers to jointly write descriptive memos. Further analysis was completed through discussions and peer debriefings to identify categories and complete analytic memos. Further analysis was implemented to identify categories and create analytic memos to describe each category. This iterative process continued as the categories were combined into themes using analytic memos to identify themes and then document a clear description of each theme (Portney et al., 2009).

Results

The aim of this study was to determine how the residents' quality of life and satisfaction were impacted after living in a technology aided smart home for the last year. The results of this research found that there were five major themes related to the effectiveness of the technology within the home and the perceptions participants had of their experiences within the home, as indicated in Figure 1. The themes include: (Theme 1) *Life is Easier with Smart Components;* (Theme 2) *Spreading Our Wings Within the Community;* (Theme 3) *Navigating Roommate Boundaries;* (Theme 4) *Metamorphosis into Independent Adults; and* (Theme 5) *Understanding What Independence Really Means*. Some participants' responses representing each of these themes are presented in Table 1.

Figure 1:

The Five Themes of This Study and Their Relationship with the Smart Home

Theme 1: Life is Easier with Smart Components

This study found that smart components within the home aided the residents' personal growth with the use of technology such as Alexa and the GrandCare system. GrandCare is a remote monitoring system that is used to monitor, communicate, and engage with users through a tablet interface (GrandCare Systems, 2022). Both smart systems were frequently and independently utilized by residents, as they provided audible reminders and instructions on how to perform various tasks. Results identified an increase in the feelings of safety within the home due to the smart components which automatically locked the doors and safety features, such as the non-burn feature on the conduction stovetop. Residents were satisfied with the performance

of these smart components; however, all participants also identified barriers to the use of technology within the home. One identified barrier was when technical errors were addressed it often led to the residents having to re-learn the technology, which caused further frustrations with the AT. Additionally, families felt as though the main reason residents were not using much of the technology was related to the residents' lack of training to implement the tools.

Theme 2: Spreading our wings within the community

As the residents started to increase their independence, they spread their wings within the community. All participants noted that the residents were participating in meaningful activities within the community through various clubs, sports, or volunteering opportunities. Residents reported positive experiences participating within the community overall. However, several difficulties obtaining dependable transportation occurred. One specific accessible public transportation service was noted to be unreliable and many of the residents were forced to rely on family or the DSPs for transportation to their scheduled activities.

Theme 3: Navigating Roommate Boundaries

A new aspect of life that the residents experienced, due to the increase in their independence, was trying to adapt to living with non-familial roommates. It was difficult for them to learn how to live with new individuals because of variances in daily routines, personal priorities, and personal quality standards for IADL tasks. Residents experienced a few relationship challenges during this first year of living together due to disagreements and perceived exclusions from activities. Amazingly, the residents successfully navigated these boundaries through DSP and familial support and discussions. Residents expressed willingness to continue improving communication among their housemates in order to live more cohesively.

Theme 4: Metamorphosis into Independent Adults

With the prospect of a new, independent living opportunity, the residents expressed that they felt very anxious and excited prior to occupancy of the smart home. Most of the residents were able to smoothly transition into the home, however, all participants noted that the pandemic negatively impacted their transition. Residents adapted to living away from their families faster, as the pandemic restricted the ability of their families to visit. The strict regulations on visitations outside of your immediate home due to COVID-19 also impacted the transition of the parents' roles in their sons' lives greatly, because of the sudden feeling of being distanced from their sons. Nonetheless, this seemed to be a blessing in disguise as the research results revealed that the timing of the pandemic along with the smart home technologies fostered a quicker evolution toward independence. Areas in which the resident's independence grew were the ability to use technology to perform household chores and order transportation services. Parents found the opportunity for their sons to live with same-aged peers simultaneously increased their use of technology and ability to grow socially. Although the residents evolved since they began living in the smart home, all stakeholders hoped the residents would be able to continue increasing their independence.

Theme 5: Understanding What Independence Really Means

When researching the effects of this living situation on multiple individuals, the data revealed the participants may be experiencing differing perceptions. While all parties held a unified goal for increasing the residents' independence, aspects of the smart home were not understood similarly by all the participants. Both parents and staff voiced their perceptions of the other party's beliefs regarding the residents' experiences living in the smart home. Parents felt that staff were giving residents too much independence and should spend more time coaching

residents on technology and their personal growth. Parents also perceived instances of ineffective

communication exchanges with staff concerning residents' health and safety, further

demonstrating the divide in perceptions of family and staff involvement with the residents.

Conversely, staff shared their perceptions of meditating resident disputes, supervising residents,

managing technological and housing concerns, and managing misperceptions of their role in

IADL chores around the home. Evidence of differing perceptions of the staff roles and residents'

responsibilities when living independently emerged. Parents revealed stress with the changes

and transition to the new living arrangement for their sons. Although their sons were residents of

the smart home, the parent(s) continue to advocate for their sons and frequently discussed

concerns with staff. Life changes require adjustments from all stakeholders, with the smart home

offering many positive options for each of these residents.

Table 1:

Selected Participant Responses, Representative of this Study's Themes

Theme	Participant Responses		
Life is Easier with Smart Components	Resident: "*Um, I like the a-a-Alexas because-they are very helpful because… uh you can say show me the schedule, show me your to-do list. I like that cause it will tell you what you have to do…*"	Parent: "*yeah because he can ask how to spell a word or you know his phone now is programmed with big print so um that's just been invaluable.*"	Staff: "*they really provided individualized, adaptive solution that allows someone to do something more independently that's where we really see the utility of, um, the technology at work.*"
Spreading Our Wings Within the Community	Resident: "- *I like to go to the (local sports team) games, or, to, see, my my neighbor…I like to go to some of that stuff. And, um, I like to volunteer a lot*"	Resident: "*I do like activities like I do swim team on Saturdays sometimes I hangout with my mom and dad sometimes I come back I chill relax watch tv*"	Resident: "u*hhh right now with that I'm struggling with that because I am on Access and Access is kind of neh not working at all*"
Navigating Roommate Boundaries	Resident: "*Um living with roommates is a little bit it's a little hard and tricky*"	Resident*: "Well, uh. We're getting in the groove of knowing R1 and R2 a little bit better.*"	Resident: "*we like to hang out, ummm, socialize, do things like go see movies or go bowling…*"
Metamorphosis into Independent Adults	Resident: "*It's just made my… like I said it (referring to smart home) makes my life a little easier and it um I'm able to ya know do do more things on my own*"	Parent: "*I think he's definitely grown in a lot of ways*" "*we really want him to become as independent and I don't want them doing things for him*"	Staff: "*I've seen a lot of growth there um. I've seen a lot of growth as far as like relationships and maturity.*"
Understanding What Independence Really Means	Parent: "*but I it concerns me that we all everybody involved with the situation wants certain things to happen for independence but I don't know how real that is because there are certain things that are not gonna happen it doesn't matter how much we wish for them to happen the reality of the situation is there not*"	Parent*: "I know that staff is not there to clean and I understand that but I and I don't know how much this goes on because one I'm not there ya know, we leave that piece to them that we're not involved in…*"	Staff: "*that was a time where, ya know, I'm all about the guys doing things themselves, but, ya know, sometimes you jus-just have to step in and-and-and make sure that the environment is clean and safe*"

Discussion

This study aimed to determine how the residents' quality of life and satisfaction were affected after living in a technology-aided smart home for the last year. The AT in this Midwestern smart home (specifically the Alexa, automatic door locks, conduction stovetop, and GrandCare system) allowed for residents to perform more of their ADLs and IADLs successfully, with less supervision. The ability of AT to increase this occupational performance was also seen in Wagner et al.'s 2019 study. This study also reflected similar results to Arthenat et al. (2020) and Pradhanet et al.'s (2018) studies as residents' parents and DSPs perceived that the residents' safety was increased in the smart home, a concern of the residents identified in the pre-smart home move-in study by Kennedy et al. (2020) within the theme "I Need a Little Help on That". The residents' DSPs facilitated this heightened perception of safety via remote supervision, with a lower DSP to resident ratio compared to the levels residents received in previous residential settings with results similar to Stokke et al.'s (2021) safety findings with telecare. The results of this study reflect an improvement upon the concerns of Albers and Schott's 2021, "Some things are not so good" subtheme, identified as the residents' prepared for occupancy of the smart home.

Another strength of this smart home was the prioritization of self-directedness. As identified in Shipton & Lashewicz's 2017 study, this was seen as a positive indicator by parents, residents, and staff of a high-quality group home. Albert & Schott also observed a positive correlation between residents' self-directedness and improved QoL in their 2021 study. Prior studies concurred that group home residents needed more input regarding housemate selections (Leach, 2016; Reindl et al., 2016; and Roos & Søndenna, 2020). Although residents in this study

did not have a direct influence in selecting their housemates, they knew they would be living with individuals who had similar independence goals as themselves.

Although the residents did not explicitly identify feeling lonely in the smart home, their reports of anxiety and perceived exclusions indicated they may have experienced loneliness. Despite evidence that supported living fostered the most community opportunities, feelings of loneliness were also attributed to participants across several group settings (Bigby et al., 2017 Isaacson et al., 2014; Bigby et al., 2017; Ioanna, 2020; Leach, 2016). In a prior study by Ejaz et al. (2015) feelings of loneliness were exacerbated by the turnover of DSP staff. In contrast to Ejaz's findings, the Midwestern smart home studied in this research experienced stable staffing since both caregivers interviewed (out of several) have maintained employment at this site during the two years of this study and the preceding study. Feelings of loneliness may have been influenced by the abrupt changes caused by the COVID pandemic lockdown coinciding with the residents' move-in timing. Positive feelings for socialization were provided by the parents and DSPs through continued implementation of Albers and Schott's "We've been holding on for so long … It's not easy to let go now" (p. 19) and "Most things are good" (2021) subthemes (p. 23). These subthemes discuss the role parents and staff still play in assisting residents with daily tasks (e.g., transportation, cleaning, meal preparation, goal setting) (Albers & Schott, 2021), which create continued social interaction opportunities for residents.

The results of this study aligned with current literature on AT effectiveness and the lives/journeys of smart home residents with disabilities striving towards independence. Although there was an abundance of AT available for residents of the smart home, only a small portion of AT was routinely utilized. Ocepek et al. (2013) found similar results with an older population of disabled adults. This low AT usage rate may have occurred as a result of residents' and DSPs'

lack of awareness or training for all the ATs available (Boot et al., 2018; Clifford et al., 2018).

Both DSP knowledge and residents' use of AT have been impacted by technological issues, a

mismatch of the residents' needs with the AT (Maich et al., 2019), and potentially the COVID-19

quarantine restrictions. The residents are "*Still learning, but* [they] *want to do it* [themselves]"

and thus, are anticipated to continue skill development with AT in the future (Alber & Schott,

2021, p. 21-22). Successful AT implementation may have also been limited due to the impact of

residents' low satisfaction with seemingly unreliable transportation services ordered on

technological devices, like smartphones. These reported incidences from residents align with

Levasseur et al.'s 2016 study stating that poor implementation of AT aligns with poor

transportation.

    Improvements were seen in the concerns encompassed by Kennedy et al.'s (2020) study

theme "I Need a Little Help on That," while those encompassed in their "Slowly Learning Some

Different Things About Each Other" were continuing along a slow progression (p. 19-21). The

hope of their third theme, "Go Far and Be Smart" has been actualized, as the residents of the

Midwestern smart home have enjoyed their lives in the home to this point. The transition into the

home was also very emotional for both the residents and their parents. Rough transitions are only

one of the "Impact[s] of smart home living [being] far reaching" which were viewpoints still

expressed by the residents' parents after the residents had lived in the home for a year (Albers

and Schott, 2021, p. 17-19).

Limitations

    The number of subjects involved in this study was limited to the small number of

residents at this single residence, their parents, and DSPs who were involved in the prior two

studies (Kennedy et al., 2020; Albers and Schott, 2021). Because this study was designed to

compare change(s) within the same individuals over three years, its' results may not be generalizable to other individuals or programs. Additionally, the findings of this study relied solely upon self-reported data that may have contained biased statements. Biased responses also may have arisen due to subjects providing answers they believed to be socially acceptable or desirable to the researchers (Taylor, 2017). This study supports the use of AT for increasing group home residents with ID/DD's self-perceived independence and autonomy, as well as residential and caregiver-perceived safety. Yet, more research is needed to determine whether the AT in the home was the source of these results as opposed to other features of the shared living arrangement or if stakeholder bias was reflected in the data.

Conclusion

The purpose of this study was to explore the lived experiences of four residents in a pilot smart home and determine if their satisfaction and participation were influenced by this living arrangement. Five themes emerged from analysis of the data: *Life is Easier with Smart Components, Spreading Their Wings Within the Community, Navigating Housemate Boundaries, Metamorphosis into Independent Adults*, and *Understanding What Independence Really Means.*

Life is Easier with Smart Components

This theme refers to the use of smart technology embedded in the home that aided the residents' abilities to improve their independence levels despite technological challenges. Data included stakeholders' opinions that additional training on the AT would have positively benefited the residents.

Spreading Their Wings Within the Community

This theme describes the overall positive interactions of the residents within the community despite the limitations residents encountered with public transportation services.

Navigating Housemate Boundaries

Participants mentioned that challenges and adjustments were needed when living with new housemates. Yet residents were motivated to continue to navigate these relationships with assistance from care providers.

Metamorphosis Into Independent Adults

The transition period for all stakeholders involved an evolution for the first year of living in this pilot home amidst a pandemic. Many of the stakeholders expressed hope for continued growth as the residents continue to get acclimated to their AT options, living arrangements, and housemates.

Understanding What Independence Really Means

While all stakeholders were aiming for the same goal of residents' independence and QoL, this theme shows the differences in perception of what independence should be for the residents, and how the ideal level of independence differs depending on the stakeholder's viewpoint.

Overall Findings

The findings of this study were consistent with current research focusing on technology use and current living options for adults with ID/DD. However, this study uniquely involved smart home technologies to move towards remote care providers for persons with DD, allowing greater independence for residents who choose to move from family settings to supported living arrangements. This study was limited to one Midwestern smart home with four residents, resulting in a small sample size. Future research into this topic would benefit adults with ID/DD and their caregivers and stakeholders to continue to examine the satisfaction and effectiveness of various long-term smart home living options.

This study occurred in a three-year longitudinal format to compare the residents' hopes and concerns prior to living in the home, to their satisfaction and participation levels just after moving in, and a year after living in the smart home. By gaining insight into the perceptions of smart home living through stakeholders, this research provided the valued residents' own voices of their improvements despite the transition period having lasted longer than expected for the stakeholders. The residents learned to live with new individuals and navigate housemate relationships; a concern for both the parents and the residents prior to moving into the smart home. Differing perceptions were still apparent between staff, parents, and residents about the ideal level of independence at the conclusion of data collection. However, as the longitudinal data has shown, improvements were evident over time and are expected to continue as the residents advance their skills and gain comfort within their home.

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Appendix A

Interview Guides (Adapted from Albers & Schott, 2021)

Resident Interview Guide

Questions about the "Forever, Home"

1. What do you like most about living here?

2. Is there anything you would like to be different?

3. Tell me about what it's like living with other people.

4. What kinds of things do you like to do with each other?

Questions about AT in the "Forever, Home"

1. Please tell me about what the technology in the home is like.

   a. Can you tell me what parts of the technology are helpful?

   b. Can you tell me about the piece of technology in the home that is your favorite?

   c. How often do you use the assistive technology?

   d. Describe how the technology has made you safer and help you do things on your own

in the Forever, Home.

Questions about Daily Life and Responsibilities

1. Tell me about what you do in a typical day.

   a. Around what time do you get up?

   b. Do you make your own meals?

       i. If you do not, who does?

       ii. If you do, can you describe how you make your typical meals (breakfast,

          lunch, and dinner)?

   c. Can you describe the daily routines you have?

2. What kinds of chores do you do in the Forever, Home?

a. Can you describe how the chores are broken up?

3. Tell me about where you work or volunteer.

a. About how much time a week do you spend at work?

b. What do you like about working? What do you not like?

4. What do you like to do in your free time?

a. If you could add an extra piece of technology to your home, what would you add?

b. How has living here changed how you do the things you like to do? How has it been

easier? How has it been harder?

5. Can you describe which clubs or groups you are a part of?

6. How do you get to _____ (work, leisure, activities, etc.)?

Questions about Support Needs

1. What kinds of activities do you use assistive technology with at the "Forever, Home?"

2. Can you describe what activities you need help with from your service provider?

3. In what ways has your life changed after moving into the Forever, Home?

Parent Interview Guide

Profile and Background

1. What were your primary roles in (insert resident's name) life before he/she moved into the Forever, Home?

    a. How have they changed now?

Questions about the Resident's Current Living Situation

1. How has this change for _____ been different from what you expected? Similar?

2. Describe some of your hopes for _____. Are there any concerns you have?

3. In your opinion, describe the activities _____ needed the most help with.

4. Which tasks, if any, would you like to see _____ be able to do more on their own?

    a. Have you seen _____ be able to do these activities on their own?

Questions about the Resident's Support Needs

1. What services are helping _____ in the home?

    a. What are other services that could help _____?

2. What are your thoughts about the technology in the Forever, Home?

    a. What type of technology, if any, do you feel that has helped _____ the most?

    b. Are there any other types of technology you would like to see added?

    c. Do you have any concerns about the safety of the technology in the Forever, Home? If so, what are they?

3. In what ways does the technology meet _____'s needs?

Questions about Present Living Situation

1. What has been the easiest part of transition for _____? The most difficult?

2. How prepared was _____ for this transition?

3. Does the Forever, Home fulfill the hopes you had for _____?

4. Do you still have any concerns for _____ after transitioning into the new house?

LADD Staff Interview Guide

Profile and Background

1. Tell me about your role in the Forever, Home?

a. How has it changed?

2. Tell me your thoughts about working at an innovative smart home model.

Questions about the "Forever, Home"

1. What were your hopes for the "Forever, Home?"

a. How well have these been met?

2. Can you describe how the technology that is used in the "Forever, Home" has helped the

residents and your role with them?

a. Is there any other technology you think would help the residents?

3. What designs do you think were made with the residents' family in mind?

4. Describe how your original concerns have been addressed.

a. What concerns do you still have for the Forever, Home?"

5. Can you describe how the technology has helped with the resident's safety and ability to do

things on their own?

Possible Challenges

1. Can you tell us some difficulties you have had providing care for the residents thus far?

2. Can you tell us about any issues with the floorplan of the home?

3. Can you tell us about any issues you have had with the technology?

Other Questions

1. Is there anything else you would like to tell us about working in the "Forever, Home" so far?

Resident Focus Group Guide (Adapted from Albers & Schott, 2021)

Questions about Group Relationships

1. How would you describe your relationships? (Friends/roommates/acquaintances)

a. What kind of things do you like to do together?

b. What do you like to do with your roommates when you are at home?

Questions about Current Living Situation

1. What do you like about living in the Forever, Home?

2. What are things you don't like about living in the Forever, Home?

3. What problems do you still have doing things in the house?

4. What assistive technologies do you have that help you with any of these problems?

5. How do you get to the things you want to do that are away from your home?

Questions about the "Forever, Home"

1. Can you explain what you were worried about when you moved into the Forever, Home?

a. Does anything about the Forever, Home worry you now?

2. How does the Forever, Home differ from what you thought it would be like before you moved

in?

3. What are your thoughts about the level of safety in your home?

*Open up the discussion for residents to share photo(s) of their favorite assistive technology if

they chose to participate.

4. Is there anything else anyone would like to add?

Appendix B

Consent & Assent Forms (Adapted from Albers & Schott, 2021)

Resident Consent Form (On Behalf of Themself)

Summary

Our names are Kate Lopez, Allison Antonaccio, Olivia Campbell, Caitlin Regan and Rory Thomas. You are being given the chance to take part in a research study through Xavier University. The goal of this project is to study the point of view of the people living in the "Forever, Home" about their satisfaction living in the home over the last year. You were invited because you are living in the "Forever, Home," and took part in at least one of the last two studies.

Full Details

Why You Are Being Asked to Take Part

You are being asked to take part in this study because you have lived in the "Forever, Home" for the past year. Your point of view on the "Forever, Home" and how you feel about living there are important to this study.

What You Will Be Asked to Do

You will be asked to take part in a talk about the "Forever, Home." This talk should not take more than thirty minutes to do. You may also bring photos, which could be of the outside or inside of the house, if you would like to. These photos could include parts of your home that may help you or may make it harder for you to do things in your life. We do not want to see anyone else in the photo, just the home. We will take notes from observing the photos. There is also

another talk that you can take part in with you housemates at a later time. You will be asked

similar questions, and the group talk should not take longer than one hour to do.

Likely Risks

There are no likely risks to you if you choose to take part in this study. You can stop doing the

talk or the group talk any time you want to and nothing bad will happen. We might show your

photos later on when we present this study to others, and we will only use your photos to talk

about what your home is like. You can still live in the "Forever, Home" if you decide to stop

doing the talk.

Benefits

There are no known rewards to you if you take part in the study, but you will get the chance to

share your thoughts and hope and fears for yourself.

Privacy

If you say it is okay, the Xavier students will tape record and/or write down what you say during

this in-person talk. If you take part in this group talk, you can also say if you will let us tape

record the group talk or not. The details will include your answer to questions about things like

your current home life, the people who help you outside of your home, and your

satisfaction/dissatisfaction with the "Forever, Home." The students will take out or change any

details in the written or tap-recorded details that could be used to identify you. The Xavier

students will be able to see all of the details you talk about. We will not match what you say with

your name. We will keep the written and tape-recorded details in a locked drawer or research

locker that can be opened only if the teacher says it is okay. We will keep the details with your

name and the details with your name taken out in different locked drawers or research lockers. At

the end of the study (2022), we will erase the tape-recorded details and keep the written details for another three years (2025).

Not taking part in this study will have NO EFFECT ON YOUR SPOT IN THE "FOREVER, HOME" OR ANY FUTURE SERVICES you may get from Xavier University. You CAN LEAVE THE STUDY AT ANY TIME WITHOUT BEING IN TROUBLE.

If you have any questions during the study, you may contact Kate Lopez. Questions about your rights as a research subject should be directed to Xavier University's Institutional Review Board at (513) 745-2870, or irb@xavier.edu.

If you decide to take part in the study, please sign this form. You will be given the chance to have a copy of this form to keep for yourself.

_____   _____

Resident Signature   Date

_____   _____

Witness Signature   Date

_____ 👍 I want to have this talk about me using technology.

_____ 👎 I do not want to have this talk about me using technology.

_____ 👍 I say that it is okay to have this talk about me audio recorded. My face will not be recorded.

_____ 👎I say that it is not okay to have this talk about me audio recorded. My face will not be recorded.

_____ 👍I understand that if LADD says we cannot have this talk face-to-face, we will meet over Zoom.

_____ 👎I do not understand that if LADD says we cannot have this talk face-to-face, we will meet over Zoom.

_____ 👍I say that it is okay for the students to ask my parent(s) questions about me.

_____ 👎I say that it is not okay for the students to ask my parent(s) questions about me.

_____ 👍I say that it is okay for the students to ask my caregiver(s) questions about me.

_____ 👎I say that it is not okay for the students to ask my caregiver(s) questions about me.

_____ 👍I say that it is okay for me to take part in a group talk later on.

_____ 👎I say that it is not okay for me to take part in a group talk later on.

_____ 👍I say that it is okay for me to have this future group talk about me audio recorded. My face will not be recorded.

_____ ☞I say that it is not okay for me to have this future group talk about me audio recorded.

My face will not be recorded.

THE DATE APPROVAL STAMP ON THIS CONSENT FORM INDICATES THAT THIS

PROJECT HAS BEEN REVIEWED AND APPROVED BY XAVIER UNIVERSITY'S

INSTITUTIONAL REVIEW BOARD.

Resident Assent Form

I, _____, know that my parent(s) or people who take care of me have

said that it is okay for me to talk about my living experience at the "Forever, Home." This study

will be done by students from Xavier University and people who work at LADD. I am doing this

because I want to. I have been told that I can stop at any time I want to and that nothing bad will

happen to me if I decide to stop.

_____   _____

Resident Signature   Date

_____   _____

Witness Signature (Someone other than Parent/Guardian)   Date

_____ 👍I am saying YES to having my talk with the Xavier Students audio recorded. My face

will not be recorded.

_____ 👎I am saying NO to having my talk with the Xavier Students audio recorded. My face

will not be recorded.

_____ 👍I am saying YES to letting my parent(s) talk with you about me.

_____ 👎I am saying NO to letting my parent(s) talk with you about me.

_____ 👍I am saying YES to let you talk to my caregiver about me.

_____ 👎I am saying NO to let you talk to my caregiver about me.

_____ 👍I say that it is okay for me to take part in a group talk later on.

_____ 👎I say that it is not okay for me to take part in a group talk later on.

_____ 👍I say that it is okay for this future group talk to be audio recorded. My face will not me recorded.

_____ 👎I say that it is not okay for this future group talk to be audio recorded. My face will not me recorded.

THE DATE APPROVAL STAMP ON THIS CONSENT FORM INDICATES THAT THIS

PROJECT HAS BEEN REVIEWED AND APPROVED BY XAVIER UNIVERSITY'S

INSTITUTIONAL REVIEW BOARD.

Parent Consent Form

Summary

Our names are Kate Lopez, Allison Antonaccio, Olivia Campbell, Caitlin Regan and Rory Thomas. You are being offered the chance to take part in this portion of a research study through Xavier University. As you may already know, the goal of the project is to study the point of view of the residents of the "Forever, Home" about their thoughts about living in the home over the last year. You were invited because you are a parent of one of the residents of this home.

Full Details

Why You Were Invited to Take Part

You were a part of both the pre-move in and post-move in studies. Your family member has also allowed for you to share details about himself. As a parent of an adult with a developmental disability, you may know what it is like for your son to live in the "Forever, Home." This makes what you know about your son's home life important to this study.

What You Will Do in the Study

You will be asked to take part in a talk about what it is like for your family member to live in the "Forever, Home." We will ask you about twenty questions in the talk, and we may ask you to add to your thoughts. We expect most talks to last between twenty and thirty minutes.

Likely Risks

There are no likely risks to you if you take part in this study.

Benefits

There are no known rewards to you if you take part in the study, but you will get the chance to share your thoughts and hopes for yourself or someone in your life.

Privacy

If you agree, the Xavier University students will audio record and/or write down your answers during this talk. The details will include your answers to questions about things like your son's life in the "Forever, Home," your son's direct service providers, and your thoughts on the technology in the "Forever, Home." The students will take out or change any detail which could be traced back to your name. The Xavier students, their instructor, and Mrs. Lopez will all be able to see details tied to the name of the people in the study. We will not match your own details to your name. We will keep the data in a locked file cabinet that can only be opened when the instructor says it is okay. We will keep the data with your name in different locked drawers or research lockers. After transcribing each recording, we will erase these tape-recorded details and keep the written details for another three years (2025).

Not taking part in this study will have NO EFFECT ON YOUR SON LIVING IN THE "FOREVER, HOME" OR ANY FUTURE SERVICES you may get from Xavier University. You are FREE TO LEAVE THE STUDY AT ANY TIME WITHOUT PENALTY.

If you have any questions during the study, you may contact Kate Lopez. Questions about your rights as a research subject should be directed to Xavier University's Institutional Review Board at (513) 745-2870, or irb@xavier.edu.

If you decide to take part in the study, please sign this form. You will be given the chance to have a copy of this form to keep for your records.

I have been given details about this research study and its risks and rewards and have had the chance to freely ask questions and to have my questions answered to my liking. I freely give my consent to take part in this research project.

_____   _____

Signature   Date

_____ 👍I give Permission for this talk to be audio recorded. My face will not be recorded.

_____ 👎I do not give Permission for this talk to be audio recorded. My face will not be recorded.

_____ 👍I give my permission to give this talk over Zoom.

_____ 👎I do not give my permission to give this talk over Zoom.

_____ 👍I understand that if LADD says we cannot meet face-to-face we will meet over Zoom.

_____ 👎I do not understand that if LADD says we cannot meet face-to-face we will meet over Zoom.

THE DATE APPROVAL STAMP ON THIS CONSENT FORM INDICATES THAT THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY XAVIER UNIVERSITY'S INSTITUTIONAL REVIEW BOARD.

LADD Staff Consent Form

Summary

Our names are Kate Lopez, Allison Antonaccio, Olivia Campbell, Caitlin Regan and Rory Thomas. You are being offered the chance to take part in a research study through Xavier University. The goal of this project is to study the point of view of the residents of the "Forever, Home" about their thoughts about living in the home over the last year. You were invited because you are a parent of one of the residents of this home.

Full Details

Why You Were Invited to Take Part

As a direct service provider at the "Forever, Home," you may know about the technology used and the services in place for the people living in the "Forever, Home."

What You Will Do in the Study

You will be asked to take part in a talk about what it is like to work in the "Forever, Home." We will ask you about twenty questions in the talk, and we may ask you to add to your thoughts. We expect most talks to last between twenty and thirty minutes.

Likely Risks

There are no likely risks to you if you take part in this study.

Benefits

There are no known rewards to you if you take part in the study, but you will get the chance to share your thoughts about the "Forever, Home."

Privacy

If you agree, the Xavier University students will audio record and/or write down your answers during this talk. The details will include your answers to questions about things like your experience working in the "Forever, Home" and your thoughts on the technology in the "Forever, Home." The students will take out or change any detail which could be traced back to your name. The Xavier students, their instructor, and Mrs. Lopez will all be able to see details tied to the name of the people in the study. We will not match your own details to your name. We will keep the data in a locked file cabinet that can only be opened when the instructor says it is okay. We will keep the data with your name in different locked drawers or research lockers. After transcribing each recording, we will erase these tape-recorded details and keep the written details for another three years (2025).

Not taking part in this study will have NO EFFECT ON YOUR POSITION WORKING IN THE "FOREVER, HOME" OR ANY FUTURE SERVICES you may get from Xavier University. You are FREE TO LEAVE THE STUDY AT ANY TIME WITHOUT PENALTY.

If you have any questions during the study, you may contact Kate Lopez. Questions about your rights as a research subject should be directed to Xavier University's Institutional Review Board at (513) 745-2870, or irb@xavier.edu.

If you decide to take part in the study, please sign this form. You will be given the chance to have a copy of this form to keep for your records.

I have been given details about this research study and its risks and rewards and have had the chance to freely ask questions and to have my questions answered to my liking. I freely give my consent to take part in this research project.

_____   _____

Signature   Date

_____ 👍I give Permission for this talk to be audio recorded. My face will not be recorded.

_____ 👎I do not give Permission for this talk to be audio recorded. My face will not be recorded.

_____ 👍I give my permission to give this talk over Zoom.

_____ 👎I do not give my permission to give this talk over Zoom.

_____ 👍I understand that if LADD says we cannot meet face-to-face we will meet over Zoom.

_____ 👎I do not understand that if LADD says we cannot meet face-to-face we will meet over Zoom.

THE DATE APPROVAL STAMP ON THIS CONSENT FORM INDICATES THAT THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY XAVIER UNIVERSITY'S INSTITUTIONAL REVIEW BOARD.

Appendix C

Recruitment Scripts (adapted from Albers & Schott, 2021)

Resident Recruitment Script

Hello! My name is Kate. I'm here to talk to you about a study I am doing with four Xavier students. Do you remember doing a study with Xavier students last year? You may have talked to Kylie or Caroline. They asked you about your experience after moving into the "Forever, Home." Well now, you will talk about what life has been like living in the "Forever, Home" for one year now. The new students and I would like to know about the technology in the home, and how living here has made you feel. We would also like to talk with you and your housemates together as a group.

The students and I would like to meet and talk with you. However, you can choose if you want to talk to them or not. Your choice will not affect your place in the "Forever, Home." People outside of the study will not know what you said during your talk.

Would you be comfortable meeting the students and I in-person? If so, we will all be following LADD's COVID-19 Pandemic Response Procedures. This includes wearing a mask and sanitizing our hands. We would also keep six feet of distance between everyone. If not, you can also talk to us over a video Zoom call.

Do you have any questions for me? Would you like to participate in the study? Even if you say yes now, you can say no later.

Thank you!

Parent Recruitment Script

Hello! My name is Kate Lopez and I work for LADD. Four Xavier students and I would like to ask if you are interested in participating in a study on the "Forever, Home" residents. If you remember from last year, you participated in a similar research study. This study was about your son's life as they first moved into the "Forever, Home." Well now, we would like to know what it has been like for (insert son's name), as they have lived in this home for one year now. The Xavier students and I are interested in hearing about your personal thoughts and feelings of your son living in this home so far. We also want to know if you think the support and technology within this home has positively or negatively impacted your son's life.

Would you be comfortable meeting the students and I over a secure, virtual Zoom call? If not, we can also talk with you face-to-face in a private room following LADD's COVID-19 Pandemic Response Procedures. This includes wearing a mask, sanitizing our hands, and keeping six feet of distance between everyone.

During the (approximately) half-hour interview, we plan to ask questions about your son's life in the "Forever, Home" thus far. Your answers will not affect your son's place in the "Forever, Home project." What you share with us will also not be shared with anyone outside the study.

Finally, are there any questions you have about this study?

Thank you!

LADD Staff Recruitment Script

Hello! This is Kate Lopez from LADD. I am currently working with four Xavier students on a study about the "Forever, Home" residents, and would like to know if you are interested in participating. If you remember from last year, you were part of a similar research study. This study was about residents' lives as they first moved into the "Forever, Home." Well now, the students would like to know what it has been like for you and the residents after one year now. They are interested in hearing your thoughts about the progress of the project so far. The students also want to know about the effectiveness of the program services provided to the residents in the "Forever, Home."

Would you be comfortable meeting the students in-person? If so, you all will need to follow LADD's COVID-19 Pandemic Response Procedures. This includes wearing a mask, sanitizing our hands, and keeping six feet of distance between everyone. If not, you can also talk to the students over a virtual Zoom call.

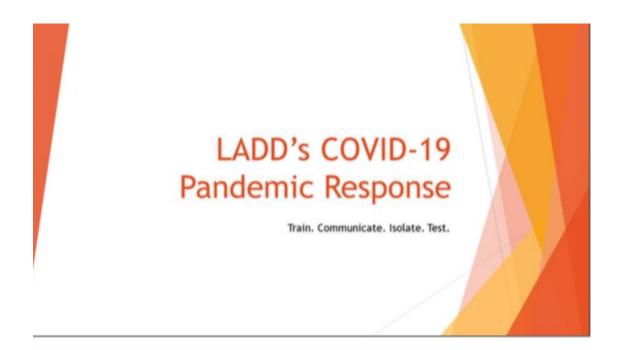During the (approximately) half-hour interview, the students plan to ask questions about your time working on this project thus far. Your answers will not affect your job in the "Forever, Home." What you share with them will also not be shared with anyone outside the study.

Finally, are there any questions you have about this study?

Thank you!

Appendix D

LADD's COVID-19 Pandemic Response Procedures

Level 0 - Normal Operations   Level 0

▶ **People served** sustain normal support
▶ **Staff** utilize normal procedures for hygiene and personal protection
▶ **Cleaning procedures** are performed as usual
▶ **Nurse & Supervisors** provide routine education on hygiene and personal protection
▶ **Internal communication** is as needed
▶ **External communication** is provided at normal intervals
▶ **Supplies** are purchased and stockpiled as required

Level 1 - General Precautions   Level 1
CDC warns of risk to general US population

▶ **People served** sustain normal support + additional hygiene education provided
▶ **Staff** utilize normal procedures for hygiene and personal protection
▶ **Cleaning procedures** are performed as usual. Advanced procedures are taught.
▶ **Nurse & Supervisors** provide proactive refreshers on hygiene and personal protection
▶ **Internal communication** is proactive, explaining the risk outlined by the CDC
▶ **External communication** is provided at normal intervals
▶ **Supplies** are purchased and stockpiled as required. Begin to advance buy material.

Level 2 – Advanced Procedures   Level 2
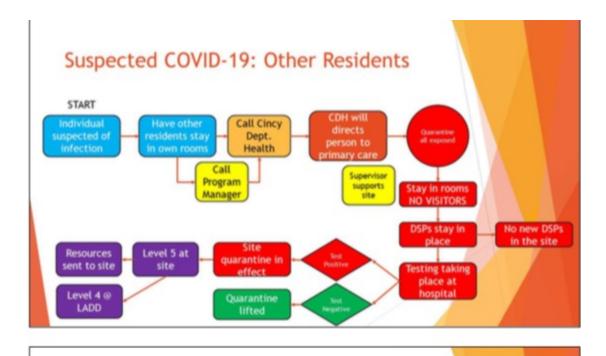### Ohio Declares State of Emergency

- **People served** are educated on the situation. Minimize physical contact. Reduce unnecessary travel when possible. Visitors are only allowed in certain areas and those areas are cleaned once finished.
- **Program Leaders** review LADD policies and update site specific plans
- **Program Leaders** identify AT RISK people served
- **Staff** increase levels of hand washing begin using PPE for physical contact.
- **Identify NON-ESSENTIAL staff** - Prepare non-essential staff to work from home
- **Cleaning procedures** Advanced procedures are put into place.
- **Nurse & Supervisors** monitor advanced procedures. Obtain kits from HQ for the sites
- **Internal communication** is proactive, explaining the measures taken
- **External communication** is proactive on measures being taken at LADD.
- **Supplies** advance buy all materials.

Level 3 – Avoidance Measures   Level 3
Confirmed Cases in Cincinnati

- **People served** are limited to essential travel only. Visitors are limited to immediate family and family members must be checked for illness.
- **LADD Events moves to virtual or is cancelled**
- **Program Leaders** determine alternate program plans and enact site specific plans
- **Program Scheduler** prioritize high risk individuals with staffing
- **Staff** use PPE and limit contact.
- **Non-essential staff** works from home
- **Cleaning procedures** Advanced procedures in place - frequent cleaning of high traffic and touch areas.
- **Nurse & Supervisors** Prepare for next level of support should it impact LADD.
- **Internal communication** is proactive, explaining the measures taken
- **External communication** is proactive on measures being taken at LADD.
- **Supplies** are checked at each location to ensure proper supply. Level 3 kits disseminated. Level 5 kit to be created and ready to use.
- **Sustain** develop ways to support staff and the people LADD is effectively isolating, remotely and ensuring everyone remains connected as days turn into weeks

Suspected COVID-19: Other Residents

START

Individual suspected of infection → Have other residents stay in own rooms → Call Cincy Dept. Health → CDH will directs person to primary care → Quarantine all exposed

Call Program Manager

Supervisor supports site

Stay in rooms NO VISITORS

DSPs stay in place → No new DSPs in the site

Resources sent to site ← Level 5 at site ← Site quarantine in effect ← Test Positive ← Testing taking place at hospital

Level 4 @ LADD

Quarantine lifted ← Test Negative

Level 4 – Lockdown

Level 4

LADD has a confirmed case

- **People served** stay in place to the max extent possible. No visitors.
- **Program Leaders** - Communicate with Senior Staff frequently. Daily updates.
- **Program Scheduler** - Continue to staff via priorities. Identify gaps in coverage.
- **Staff** use PPE and limit contact.
- **Cleaning procedures** Frequent cleaning of high traffic and touch areas. Decontamination if needed.
- **Nurse & Supervisors** coordinate to ensure proper resources are shared.
- **Internal communication** is proactive, explaining the measures taken
- **External communication** is proactive on measures being taken at LADD.
- **Supplies** are checked at each location to ensure proper supply. Replenish Level 3 kit
- **Sustain** develop ways to support staff and the people LADD is effectively isolating, remotely and ensuring everyone remains connected as days turn into weeks

Level 5 – Quarantine [at Site]

Level 5

Location has a confirmed case

- **People served** - Quarantine individual. Look to move others if able.
- **Staff** that are not exposed do not enter. Go down to limited staff.
- **Cleaning procedures** Decontamination procedures.
- **Nurse & Supervisors** coordination. Nurse with outside agencies, coordinator takes lead at the home.
- **Internal communication** is proactive, explaining the measures taken
- **External communication** is proactive on measures being taken at LADD.
- **Supplies** LEVEL 5 kit deployed.
- **Sustain** develop ways to support staff and the people LADD is effectively isolating, remotely and ensuring everyone remains connected as days turn into weeks

LADD COVID-19 Communication Plan

INTERNAL COMMUNICATION PLAN

- Daily 8:30am Task Force calls
- 20 Minute daily briefing calls take place at 9:30 a.m. & 8 p.m.
- COVID-19 Response page created on LADD Intranet includes:
  - Regular updates
  - Internal FAQ's
  - Resources
- Internal update sent at least weekly on Fridays
- staysafe@laddinc.org email created to have quick response to any questions from staff, families & partners.
- Cross-departmental task force created and communication protocols for team distributed.
- Critical communication plan created and posted on intranet.

EXTERNAL COMMUNICATION PLAN

- External update sent at least weekly on Friday. Currently sent via email, social media, and posted on website.
- Assessing family communication needs to determine if we need to invest in additional resources.
- staysafe@laddinc.org email created to have quick response to any questions from staff, families & partners.
- External FAQ page posted on LADD Website.
- All LADD Events through April 15th have been postponed or cancelled. Communication sent out via email, on website & posted on social media.
- Created emergency response communication plan. (see attachment).

LADD's COVID-19 Communications Process*

*This is only a process for communications. COVID-19 response plan, including sanitizing and quarantining protocol, will take place simultaneously.

DSP notices symptoms:

Symptoms noticed → DSP notifies program manager → PM notifies Shavonne Noble, RN → DSP, with Shavonne, calls health department → Within 15 minutes of HD call, PM notifies Paul + Amy → Within 1 hour of HD call, Paul + Amy notify Susan + Molly. PM calls family of sick individual

DSP compiles contact info for families in immediate vicinity, sends to PM → PM compiles contact info for staff who had close personal contact → Molly notifies COVID Task Force → Shavonne or PM notify Paul + Amy to make them aware of HD response → Paul + Amy notify Susan + Molly to relay information → Molly notifies COVID Task Force of HD response

If HD requires testing:

PM instructs exposed staff to self-quarantine → Within 1 hour of being notified, Susan notifies Rob Zimmerman of test → CM coordinates notification to families of residents in immediate vicinity → Shavonne or PM receive testing results, notify Paul + Amy → Paul + Amy notify Susan + Molly → Molly notifies COVID Task Force and Jess

If COVID-19 confirmed:

PM notifies exposed staff about result, continue self-quarantine → Within 1 hour of finding out, Susan notifies Rob, then full board → Within 4 hours, notify families of other residents in immediate vicinity → Within 8 hours, Susan sends email to all staff → Within 12 hours, external email sent to all families + LADD partners; posted on website, social

Appendix E

LADD's Release of Information Form

<u>Release of Information from LADD</u>

I, _____, do hereby authorize LADD to release the following information:

Individual/Guardian

in regard to _X_Self or ___Name: _____:

____Primary diagnosis, age, education level, and for parents and staff to participate in this study and share information about me._____

_____

_____

_____

This information shall only be released to:

Name: **Xavier University Occupational Therapy Dept.**

Agency Name: **N/A**

Address**: 3800 Victory Parkway**

    119 Cohen Center

    Cincinnati, OH 45207

Phone #: **513-745-3814**

The information shall only be used for the following reason(s):

_____**The *Experiences of Adults with Disabilities, their Family Members, and Caregivers, in a Community-Based Supportive Home* research study.**_____

_____

_____

_____

_____

This consent will expire within one (1) year of the date signed. In addition, I may revoke this consent at any time by contacting the Manager, Quality Assurance and Compliance.

_____   _____

Signature of Individual/Guardian Consenting to the Release of Information   Date

Effective 7/99; 11/11/03; 6/11/06; 4/19/12; 10/11/17

Appendix F

Welcome Scripts (adapted from Albers & Schott, 2021)

Resident Welcome Script

Hello, our names are [Allison, Caitlin, Olivia, and/or Rory]. We are glad you told Kate you want to be in our study. We will tell you again what is going to happen to make sure that everything is still okay with you.

If you remember, you talked to some Xavier students last year. You told them about beginning your life in the "Forever, Home." Well now, we want to know what your life has been like after living here for one year. We will ask about your thoughts and feelings on the technology and support in the home. Your answers will not be shared with anyone outside this study. Your responses will not impact your place in the house.

If this all still sounds good to you, Kate is going to ask you for your permission. Then, we can begin the interview. Ask any questions you have when you have them.

Parent Welcome Script

Hello, our names are [Allison, Caitlin, Oliva, and/or Rory]. We, along with the rest of our student research group and LADD organization, would like to thank you for participating in this study about the lives of the "Forever, Home" residents. If you remember from last year, you participated in a study about your son's life upon move-in. Now, we want to know what it has been like for your son after living in the "Forever, Home" for one year.

Since you have agreed to be in this study, we would like to remind you of its aim. The aim is to discover what it is like for adults with disabilities to live in a supported living smart house, like the "Forever, Home." Your son, (insert son's name), said it is okay for us to talk to you about your thoughts on his/her life in the "Forever, Home." We want to know your thoughts on the assistive technology and support in the "Forever, Home" and how they have impacted (insert son's name)'s life so far. Your involvement in this interview will not affect (insert son's name). Your name will not be attached to the details you share by the end of this study.

If you still agree with this study, Kate is going to ask you for your permission. Then, we can begin the interview. Feel free to ask any questions at any time if you have them.

LADD Staff Welcome Script

Hello, our names are [Allison, Caitlin, Rory, and/or Olivia]. We, along with the rest of our student research group and LADD organization, would like to thank you for participating in this study about the lives of the "Forever, Home" residents. If you remember from last year, you participated in a study about the residents' lives upon move-in. Now, we want to know what it has been like for the residents after they have lived in the Forever, Home for one year.

Since you have agreed to be in this study, we would like to remind you of its aim. The aim is to discover what it is like for adults with disabilities to live in a supported living smart house, like the "Forever, Home." We want to know your thoughts on the assistive technology and support in the "Forever, Home," as well as the effectiveness and progress of the project thus far. Your answers to our questions will not impact your job at the "Forever, Home." Your name will not be attached to the details you share by the end of this study.

If you still agree with this study, [Allison, Caitlin, Rory, or Olivia] will ask you for your permission. Then, we can begin the interview. Feel free to ask any questions at any time if you have them.

Resident Focus Group Welcome Script

Hello and welcome back! Again, our names are [Allison, Caitlin, Olivia and/or Rory]. We thank you all for being here. Is everyone still okay with answering some questions as a group? We will ask about the "Forever, Home" and its impact on your life.

If you remember, you talked to some Xavier students last year as a group. You told them about beginning your life in the "Forever, Home" as a group. Well now, we want to hear from you all (again, as a group) about what life has been like after living here for one year. We will ask what your thoughts and feelings are about the house and the changes that have occurred in it. Your answers will not be shared with anyone outside this study. Your responses will not impact your place in the house.

If this all still sounds good to you, Kate is going to ask you for your permission. Then, we can begin the interview. Feel free to ask any questions at any time if you have them.