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RESEARCH ARTICLE

A Survey Assessing Privacy Concerns of Smart-Home Services Provided to Individuals with Disabilities

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Abstract

Privacy has been identified as a primary concern among stakeholders (i.e., service recipients, advocates, administrators, family) when using technology to provide residential services to individuals in need. This paper summarizes a study that distributed a survey to agencies that provide services (e.g., clinical, recreational) and resources (e.g., advocacy groups) to people with various types of disabilities (e.g., physical, sensory, intellectual, developmental) across the United States. The results led to several recommendations about how smart-home service providers can use technology in a way that promotes client privacy. In addition, we make several suggestions for how remote staff (i.e., individuals monitoring the information gathered by technology) can assist in the process of ensuring client privacy.

Keywords Disabilities · Privacy · Smart homes · Telecare · Technology

Approximately 41 million individuals in the United States have a disability (physical, sensory, intellectual, or developmental), which represents approximately 13% of the population (Kraus, 2017). As the number of individuals with disabilities in the United States continues to increase, service providers are facing increased pressure to deliver quality services in a timely manner. Moreover, U.S. population statistics demonstrate that there is a need to provide more viable options for individuals with disabilities requiring long-term residential services—both in the present and the years to come (Braddock et al., 2013). Traditional approaches of providing community-based residential services to individuals with disabilities (e.g., group homes) are often expensive, restrictive, and not sustainable (Gerhardt, 2009). Alternative technology-based service models may provide a viable substitute to meet growing service needs.

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Telecare involves providing services across distance via technology and consists of delivering continuous automatic support and care for individuals with special needs (e.g., individuals with disabilities) to allow them to remain within their own homes (Guise, Anderson, & Wiig, 2014). Telecare services often involve equipping residential units with alarms and sensors connected to a remote monitoring center. The technology provides information about the in-home activity of residents to detect potential health (e.g., seizures) and safety (e.g., falling) risks. Telecare has several potential advantages, including providing access to needed services, eliminating barriers to care, and reducing the cost to provide high-quality services (Mort, Roberts, Pols, Domenech, & Moser, 2015). Moreover, telecare may promote client independence by offering daily support and monitoring in agreed-upon ways (DiGennaro Reed & Reed, 2013).

One method of providing telecare services is via smart homes. Smart homes include both active (e.g., video and audio recordings) and passive (e.g., sensors) monitoring agents located throughout a client's residence that provide immediate access to remote staff (i.e., remote monitoring). For example, technology located within the home can detect if a resident has fallen and can alert staff that help is required (Draper & Sorell, 2012). Further, sensors on a stove could trigger an alert if a resident left a stove on after preparing a meal. Remote staff receiving the alert can either deploy staff to assist or contact the residents directly to inform them that the stove is still on.

Presently, smart homes are often used to provide services to older adults (65 years or older) and adults with intellectual and developmental disabilities (Chung, Demiris, & Thompson, 2016; Demiris & Hensel, 2008).

When using technology to provide services to individuals in need, the primary concerns of stakeholders (e.g., advocates, administrators, service recipients, family) include the risk of exploitation and invasion of privacy (e.g., Brewer, Taber-Doughty, & Kubik, 2010; Dorsten, Sifford, Bharucha, Mecca, & Wactlar, 2009; Essen, 2008; Niemeijer, Depla, Frederiks, & Hertogh, 2015). Moreover, research suggests the opinions of users can influence the successful adoption of a technology (Venkatesh, 2000), and safeguards are necessary during remote monitoring to prevent misuse (Powell et al., 2010). Thus, service providers who wish to adopt technology are faced with the challenge of determining how to use it in a way that respects individuals' personal privacy while also maintaining safe and secure living conditions.

Numerous studies have summarized the specific privacy concerns that different stakeholder groups have about the use of smart homes for adults aged 65 years or older (including some older adults with dementia; see Chung et al., 2016, for a review). Some privacy concerns include not wanting others to know when certain activities were taking place (e.g., toileting) and fear of being judged based on patterns of activity. However, Chung et al. (2016) also reported that some studies found that privacy concerns became less important for older adults when the technology meets their needs and allows them to maintain independence in their homes.

At present, the literature regarding privacy within a smart-home setting is limited due to its focus on adults aged 65 years or older, and the research needs to be expanded to include more diverse samples. For example, more research is needed to understand the specific types of privacy concerns that exist when smart-home services are provided for individuals with disabilities (e.g., physical, sensory, developmental, intellectual) across various ages. Such research is important because it cannot be assumed that privacy concerns regarding smart homes are similar across different types of service recipients (e.g., DiGennaro Reed et al., 2014).

Presently, little research exists that has investigated the privacy concerns of stakeholders when smart homes involve individuals with disabilities. Brewer et al. (2010) conducted a survey of multiple stakeholder groups (e.g., clients, advocates, administrators, case coordinators) from the state of Indiana to assess their judgments regarding privacy when providing services to individuals with developmental disabilities during overnight hours within a telecare model. The technology used within the service model included video cameras, smoke detection sensors, motion sensors, and temperature controls. Participants across the different stakeholder groups generally had positive responses about privacy within the telecare system. Additionally, participants judged the telecare model to be as private as having staff continuously present within the home.

One limitation of Brewer et al. (2010) was that the telecare model only operated during overnight hours, and judgments regarding privacy might be less favorable if the telecare system operated 24 h per day, 7 days per week. Moreover, the results did not provide detailed information about privacy concerns for each individual piece of technology used as part of the telecare system. For example, stakeholders may have no concerns when the telecare model employs a series of motion sensors, but they may have strong concerns with the addition of video cameras. Such information could help service providers develop strategies for minimizing intrusiveness.

Niemeijer et al. (2015) documented the experiences of adults with intellectual disabilities (18–60 years old) when receiving services via surveillance devices—motion sensors, electronic bracelets, and video cameras—within a residential setting. The results showed that participants' views about privacy were different for the various devices. For example, participants perceived electronic bracelets as enabling privacy but video cameras as intruding on privacy. Limitations of the study include a small sample size and possible selection bias.

The primary benefit of obtaining information about privacy concerns regarding smart homes for individuals with disabilities directly from stakeholders is to help service providers develop strategies to effectively and efficiently address these concerns. Addressing these concerns has the potential to increase the acceptability of the service model. However, given the limited body of research documenting the privacy concerns of various stakeholders when individuals with disabilities receive services via smart homes, more research is needed before definitive conclusions can be reached.

The literature would benefit from a study that (a) surveys multiple stakeholders across a variety of agencies that provide services and resources to individuals with disabilities, (b) provides information about levels of concern associated with individual technology, and (c) assesses privacy concerns across various aspects of smart homes. The purpose of this study was to ask multiple stakeholders (i.e., staff, volunteers, advocates, clients) to rate their levels of concern about the privacy of individuals with disabilities when receiving services via smart homes.

Method

Participants

Participants were individuals who responded to an invitation to complete an anonymous online survey and included paid staff members (e.g., professionals, paraprofessionals,

advocates), volunteers, individuals with disabilities, and family members of individuals with disabilities affiliated with agencies providing services (e.g., clinical, recreational) and resources (e.g., advocacy groups) to individuals with disabilities. To complete the survey, participants had to be at least 18 years old and provide their own consent. The survey link was accessed by 331 individuals.

Instrumentation

We created the survey using Qualtrics® Research Suite (http://www.qualtrics.com). Prior to completing the survey, participants were presented with an information statement and consent form. The survey consisted of three sections. The first section required participants to view a 134-s video that described how smart-home technology was used to provide services to individuals with disabilities. The video served two purposes: (a) to provide information about smart homes to participants who may not have been familiar with the service model, and (b) to ensure that all respondents had the same information about how the service model operates. The video was narrated with a voice-over and contained closed captions. Following the video, participants were required to answer one multiple-choice question about the content of the video. The question was, "Based on the video, which of the following is involved as part of the smart-home service model?" Possible answers were video cameras, motion sensors, remote coaches, and all of the above (correct answer: all of the above). The question was included as an indication of whether participants watched the video prior to answering any survey questions. We only included data from participants who answered the question correctly, which resulted in the loss of data for one participant.

The second section consisted of six questions. Questions 1–3 asked participants to rate the importance of (a) the personal privacy of individuals with disabilities when receiving long-term services, (b) the information received by technology within a smart home being stored in a way that ensures and protects resident privacy, and (c) smart-home residents meeting remote staff (i.e., individuals monitoring the information gathered by the technology) in person. Participants rated the level of importance for these questions using a 4-point Likert-type scale (1 = *not at all important*, 2 = *slightly important*, 3 = *moderately important*, 4 = *extremely important*). Question 4 asked whether meeting remote staff in person would make the technology appear less invasive to smart-home residents. Participants could answer "yes," "no," or "makes no difference."

Question 5 listed generic descriptions of five types of residential service models used to provide long-term services to individuals with disabilities; this list was not exhaustive. Participants were asked to rate how much concern they had for the personal privacy of individuals with disabilities if they were to receive long-term care within each of the service models. The service models included (a) residents living by themselves in their own homes with a staff member continuously present to provide support, (b) residents living by themselves in their own homes and supported by on-site staff who have scheduled visits, (c) residents living with and supported by family members on a full-time basis, (d) residents living by themselves in their own homes equipped with smart technology located in common living areas and supported by remote staff, and (e) residents living in a group home with at least four other residents and continuous staff support.

Question 6 asked participants to rate how much concern they had for the personal privacy of individuals with disabilities if they were to receive services within their own homes for nine pieces of technology. The technology included (a) video cameras placed in common living areas; (b) video cameras overlooking resident bedroom entrances; (c) video cameras overlooking resident bathroom entrances; (d) motion sensors located throughout the home that alert remote staff when triggered; (e) a device that allows remote staff to switch appliances off remotely; (f) pressure mats placed on couches, beds, and certain parts of the floor that alert remote staff when residents sit, stand, or lie down on them; (g) devices attached to doors and windows that alert remote staff when they have been opened or closed; (h) intercoms that allow remote staff to contact residents at any time; and (i) cellphones and telephones on which remote staff can call residents at any time. Questions 5 and 6 asked participants to rate their level of concern using a 4-point Likert-type scale (1 = *not at all concerned*, 2 = *slightly concerned*, 3 = *moderately concerned*, 4 = *extremely concerned*).

The survey concluded with participants providing demographic information for the following variables: (a) age, (b) sex, (c) ethnicity, (d) state of residence, (e) average annual household income, (f) primary role with respect to working with people with disabilities, (g) years of experience working with people with disabilities, (h) highest level of education, and (i) whether anyone in their family had a disability. If participants indicated that they had a family member with a disability, they were also asked to specify their relation to (e.g., parent/guardian, sibling, son/daughter) and current living situation (e.g., foster care, nursing care, group home) of the family member with the disability.

Procedures

We contacted leaders (e.g., managers, directors, executive staff) of 30 agencies that provided services and resources to individuals with disabilities across the United States via e-mail and requested that they distribute a link to an anonymous online survey to their members (e.g., staff, volunteers, advocates, clients). We distributed the survey link to the same 13 agencies that were included in DiGennaro Reed et al. (2014)

and included an additional 17 agencies that provided services to individuals with disabilities and had national representation; this list was not exhaustive. The selected agencies served a diverse range of populations, including individuals with autism spectrum disorder, brain and spinal injuries, multiple sclerosis, spina bifida, muscular dystrophy, and speech and language deficits (see Table 1). We asked agencies to distribute the survey link once only. Some organizations distributed the survey link via social media and by posting it on their websites.

Results

For data to be included in the final analyses, respondents had to complete 100% of the survey and correctly answer the question inquiring about the content of the introductory video. We retained data for 209 of the 331 respondents who accessed the survey link (63.1%). Table 2 displays the demographic characteristics of survey respondents. Of these 209 respondents, 27.3% (n = 57) were between the ages of 55 and 64, 75.6% (n = 158) were female, 90.9% (n = 190) reported their ethnicity as White/Caucasian, 29.7% (n = 62) reported their average annual household income as $100,000 or more, and 52.6% (n = 110) reported they had 16 or more years of experience working with individuals with disabilities. Respondents indicated living across 31 states, with the highest concentration of respondents residing in Illinois (22.0%, n = 46) and Pennsylvania (12.9%, n = 27). Most respondents identified themselves as direct service professionals (21.6%, n = 44) or licensed practitioners (18.2%, n = 38). Approximately 70% of respondents listed bachelor's (32.5%, n = 68) or master's (37.8%, n = 79) degrees as their highest level of education. Of the 209 respondents who completed the survey, 66.5% (n = 139) had a family member with a disability. Of these 139 respondents, 25.8% (n = 36) classified themselves as parents/guardians, 18.7% (n = 26) as extended family members, and 15.1% (n = 21) as a sibling. A majority of respondents indicated the current living situation of their family member with a disability was living with the respondent or another family member (56.1%, n = 78), and 12.9% (n = 18) reported they were the person within their family who had the disability.

Survey Questions

Tables 3, 4, 5 and 6 depict the results from the survey questions. Table 3 presents the results for Questions 1–3. The results show that 73.7% (n = 154) of respondents rated the personal privacy of individuals receiving long-term services as *extremely important* and 24.9% (n = 52) as *moderately important*. Next, 90.9% (n = 190) and 8.1% (n = 17) of respondents indicated that secure data storage was *extremely important* or *moderately important*, respectively. Ninety percent of respondents rated that it was either *extremely important* (69.9%, n = 146) or *moderately important* (20.1%, n = 42) for residents to meet the remote staff in person.

Table 4 displays the results for Question 4, which asked respondents whether meeting remote staff in person would make the technology appear less invasive. A majority of respondents (82.3%, n = 172) stated yes, 5.3% (n = 11) stated no, and 12.4% (n = 26) stated that it makes no difference.

Table 5 summarizes the results for Question 5. The service model that received the most ratings of *extremely concerned* was living in a group home with at least four other residents and continuous staff support (39.2%, n = 82). This service model was the only one for which the greatest number of respondents rated their level of concern as *extremely concerned*. Residents living with and supported by family members on a full-time basis was the service model for which the greatest number of respondents rated the level of concern as *not at all concerned* (24.4%, n = 51). With respect to smart homes, the greatest number of respondents rated their level of concern as *moderately concerned* (38.3%, n = 80). The service model for which the fewest respondents rated their level of concern as *not at all concerned* (8.1%, n = 17) was smart homes. Concern ratings regarding smart homes were almost identical to concern ratings for residents living by themselves with staff members continuously present within the home.

Table 6 depicts the results for Question 6. Thirty-three percent of respondents (n = 69) indicated that they were *extremely concerned* regarding video cameras overlooking bedroom entrances, whereas 36.4% (n = 76) indicated they were *extremely concerned* regarding video cameras overlooking bathroom entrances. When video cameras were located in common living areas, 39.2% (n = 82) of respondents rated their concern as *slightly concerned*, and only 16.4% (n = 34) rated it as *extremely concerned*. For five of the nine devices, the greatest

Table 1 Breakdown of populations served for the organizations contacted to distribute the survey link

Clinical population served	Number of agencies contacted
Autism spectrum disorder	4
Cerebral palsy, brain trauma, brain injury, multiple sclerosis	4
Deaf, blind, speech-language-hearing	4
Disabilities (intellectual and/or developmental)	14
Muscular dystrophy, spinal cord injuries	4

Table 2 Demographic characteristics of respondents

	n	Percentage
Age (years)		
18–24	5	2.4
25–34	40	19.1
35–44	34	16.3
45–54	53	25.4
55–64	57	27.3
65 or older	20	9.6
Sex		
Male	49	23.4
Female	158	75.6
Intersex	0	0.0
Do not wish to answer	2	1.0
Ethnicity		
White/Caucasian	190	90.9
Hispanic/Latino	8	3.8
Black/African American	6	2.9
Asian	1	0.5
Other	4	1.9
Average annual household income		
Less than $20,000	13	6.2
$20,000–$39,999	37	17.7
$40,000–$59,999	28	13.4
$60,000–$79,999	38	18.2
$80,000–$99,999	31	14.8
$100,000 or more	62	29.7
Primary role		
Volunteer	16	7.7
Direct service professional	44	21.6
Administrator/coordinator	37	17.7
Manager	22	10.5
Licensed practical nurse/registered nurse	2	1.0
Licensed practitioner (i.e., psychologist, Board Certified Behavior Analyst, social worker)	38	18.2
Other:		
Family member/self	18	8.6
Teacher/advocate/attorney	6	2.9
Counselor/job coach/training	3	1.4
Multiple roles listed	7	3.3
Not clearly defined/did not specify	16	7.7
Years of experience working with people with disabilities		
0–5	44	21.1
6–10	19	9.1
11–15	36	17.2
16 or more	110	52.6
Highest level of education		
Did not graduate high school	0	0.0
High school graduate/high school equivalency	8	3.8
Associate's degree	21	10.0
Some college	14	6.7
Trade/technical/vocational training	3	1.4

Table 2 (continued)

	n	Percentage
Bachelor's	68	32.5
Master's	79	37.8
Doctorate	16	7.7
Does anyone in your family have a disability?		
Yes	139	66.5
No	70	33.5
Relation to family member with disability		
Person with disability	18	12.9
Parent/guardian	36	25.8
Sibling	21	15.1
Spouse/partner	13	9.4
Grandparent	5	3.6
Son/daughter	11	7.9
Extended family member	26	18.7
Multiple relations listed	9	6.5
Current living arrangements (family member with disability)		
Living with you or another family member	78	56.1
Alone in his/her own home/apartment with no staff support	21	15.1
Alone in his/her own home/apartment with some staff support	13	9.4
Living in a home/apartment with three or fewer persons	12	8.6
Group home/apartment with more than four individuals living together	8	5.7
Assisted living	2	1.4
Did not specify	5	3.6

number of respondents rated their level of concern as *not at all concerned*. These devices were motion sensors (32.5%, n = 68), devices that allow remote staff to switch appliances off remotely (50.2%, n = 105), devices attached to doors and windows (43.1%, n = 90), intercoms (40.2%, n = 84), and cellphones/telephones (58.4%, n = 122).

Supplemental Analyses

We conducted supplemental analyses for respondents who indicated high levels of concern about resident privacy when receiving smart-home services. Specifically, we investigated whether respondents had high levels of concern regarding specific pieces of technology or had concerns about the use of smart-home technology in general. To conduct these analyses, we divided respondents into two groups based on their concern ratings regarding the privacy of individuals with disabilities when receiving smart-home services (Table 5). The low-concern group consisted of respondents who rated their level of concern as either *not at all concerned* or *slightly concerned* (i.e., a rating of 1 or 2 on the 4-point Likert-type scale). The high-concern group consisted of respondents who rated their level of concern as either *moderately concerned* or *extremely concerned* (i.e., a rating of 3 or 4 on the 4-point Likert-type scale).

For both groups, mean concern rating scores were calculated for the technology listed in Table 6. Independent sample *t* tests were conducted to compare mean concern ratings across

Table 3 Percentage (frequency) of respondents rating the level of importance regarding personal privacy of individuals with disabilities receiving long-term care, data storage, and remote staff

	Not at all important	Slightly important	Moderately important	Extremely important
How important is the personal privacy of adults with disabilities who receive long-term care?	0.0 (0)	1.4 (3)	24.9 (52)	73.7 (154)
How important is it for the information or data received by the technology within a smart home to be stored in a way that ensures and protects resident privacy?	0.0 (0)	1.0 (2)	8.1 (17)	90.9 (190)
How important is it for smart-home residents to meet remote staff in person?	2.4 (5)	7.7 (16)	20.1 (42)	69.9 (146)

Table 4 Frequency and percentage of respondents indicating whether meeting remote staff in person would make the technology appear less invasive to smart-home residents

Response	*n*	Percentage
Yes	172	82.3
No	11	5.3
Makes no difference	26	12.4

the two groups for all technology. We also calculated Cohen's *d* effect size measures (Cohen, 1988). Cohen's *d* values of 0.10, 0.30, and 0.50 indicate small, medium, and large effects, respectively.

The results in Table 7 show statistically significant differences between low- and high-concern groups regarding mean concern rating scores across each individual piece of technology at the 5% significance level, and all Cohen's *d* effect size measures were above 0.50. The largest effect sizes were obtained for video cameras overlooking resident bathroom entrances ($d = 0.95$), video cameras placed in common living areas ($d = 0.93$), and motion sensors located throughout the home ($d = 0.90$). Respondents in the low-concern group rated their concern about individual pieces of smart-home technology significantly lower relative to respondents in the high-concern group. Thus, respondents with high concern regarding resident privacy when using smart homes appear to have higher concern for smart-home technology in general. Moreover, we conducted a series of chi-squared tests to examine whether participant demographic variables were evenly distributed among the low- and high-concern groups. The results showed that the groups did not significantly differ across any of the demographic variables at the 5% significance level.

Next, we conducted independent samples *t* tests to compare the mean concern ratings for respondents with and without a family member with a disability regarding the different types of service models and technology. Regarding the different types of service models, respondents who have a family member with a disability expressed significantly greater concern ($M = 3.12$, $SD = 0.97$) about group homes compared to respondents who do not have a family member with a disability ($M = 2.73$, $SD = 1.01$), $t(207) = 2.73$, $p = .007$, $d = 0.40$. Respondents who have a family member with a disability also indicated significantly greater concern for service models involving the continuous presence of staff in the home ($M = 2.78$, $SD = 0.89$) compared to respondents who do not have a family member with a disability ($M = 2.51$, $SD = 0.91$), $t(207) = 2.00$, $p = .046$, $d = 0.30$. No other significant differences were detected at the 5% level of significance.

Respondents who have a family member with a disability ($M = 2.99$, $SD = 0.95$) rated their concern level significantly higher regarding video cameras overlooking bedroom entrances than respondents who do not have a family member with a disability ($M = 2.67$, $SD = 1.03$), $t(207) = 2.20$, $p = .035$, $d = 0.32$. Respondents who have a family member with a disability had significantly higher concern regarding video cameras overlooking bathroom entrances ($M = 3.11$, $SD = 0.91$) compared to respondents who do not have a family member with a disability ($M = 2.71$, $SD = 1.01$), $t(207) = 2.84$, $p = .005$, $d = 0.41$. No other significant differences were detected at the 5% level of significance.

Discussion

This study queried multiple stakeholders (staff, volunteers, advocates, clients) affiliated with agencies providing services and resources to people with disabilities to assess these stakeholders' level of concern for the privacy of individuals with disabilities when receiving services using technology. Specifically, we assessed privacy concerns relating to data storage, remote staff, different types of residential service models, and individual pieces of smart-home technology. Although we invited agencies to distribute the survey link to clients (i.e., individuals with disabilities), only 18 respondents (8.6%) identified themselves as having a disability. Thus, the results may best reflect the privacy concern ratings of

Table 5 Percentage (frequency) of respondents rating their level of concern for the personal privacy of individuals with disabilities receiving long-term care within each service model

Service model	Not at all concerned	Slightly concerned	Moderately concerned	Extremely concerned
Residents live by themselves in their own homes with a staff member continuously present to provide support.	9.6 (20)	32.1 (67)	38.3 (80)	20.1 (42)
Residents live by themselves in their own homes and are supported by on-site staff who have scheduled visits (no other support provided).	18.7 (39)	41.6 (87)	27.8 (58)	12.0 (25)
Residents live with and are supported by family members on a full-time basis.	24.4 (51)	33.5 (69)	27.8 (58)	15.3 (32)
Residents live by themselves in their own homes, which are equipped with smart technology located in common living areas and are supported by remote staff (i.e., smart homes).	8.1 (17)	33.0 (69)	38.3 (80)	20.6 (43)
Residents live in a group home with at least four other residents and continuous staff support.	10.0 (21)	21.5 (45)	29.2 (61)	39.2 (82)

Table 6 Percentage (frequency) of respondents rating their level of concern for the personal privacy of individuals with disabilities if they were to receive care within their own homes with each of the following pieces of technology

Technology	Not at all concerned	Slightly concerned	Moderately concerned	Extremely concerned
Video cameras placed in common living areas	16.3 (34)	39.2 (82)	28.2 (59)	16.3 (34)
Video cameras overlooking resident bedroom entrances	10.0 (21)	24.9 (52)	32.1 (67)	33.0 (69)
Video cameras overlooking resident bathroom entrances	8.6 (18)	21.5 (45)	33.5 (70)	36.4 (76)
Motion sensors located throughout the home that alert remote staff when triggered	32.5 (68)	31.1 (65)	25.4 (53)	11.0 (23)
A device that allows remote staff to switch appliances off remotely	50.2 (105)	26.3 (55)	12.9 (27)	10.5 (22)
Pressure mats placed on couches, beds, and certain parts of the floor that alert remote staff when residents stand, sit, or lie down on them	30.6 (64)	32.1 (67)	23.9 (50)	13.4 (28)
Devices attached to doors and windows that alert remote staff when a door or window has been opened or closed	43.1 (90)	27.3 (57)	22.5 (47)	7.2 (15)
Intercoms that allow remote staff to contact residents at any time	40.2 (84)	32.1 (67)	18.2 (38)	9.6 (20)
Cellphones and telephones on which remote staff can call residents at any time	58.4 (122)	23.4 (49)	11.0 (23)	7.2 (15)

respondents who identified themselves as service providers and administrators. Future studies can direct efforts toward including more individuals with disabilities. Based on the results, we made several suggestions for how service providers can apply the results from this study. A list of our main suggestions is included in the Appendix Table 8.

The results show that the personal privacy of individuals with disabilities receiving long-term services is an important issue for survey respondents. It is important to highlight that the survey question asking respondents to rate the importance of personal privacy was not framed specifically around the use of smart-home technology or smart-home services. We phrased the question more generally to assess whether respondents considered privacy an important issue when providing long-term services to adults with disabilities. Thus, we recommend service providers, regardless of service model, consider the privacy of clients receiving long-term residential services.

The greatest number of respondents indicated that it is extremely important for smart-home data to be stored in a way that ensures and protects client privacy. These results support findings from other studies that also identified secure data storage as an important issue when providing smart-home services (e.g., Wilkowska, Ziefle, & Himmel, 2015). The secure storage of medically sensitive information is important to ensure that service providers are compliant with U.S. federal law that prohibits sharing medical information without client or guardian consent (Health Insurance Portability and Accountability Act, 1996). It is also important that data are shared with approved individuals only and in a way that respects client dignity. Finally, it is essential to ensure the safety and security of any hardware devices, such as digital video recorders or flash drives, on which data are stored.

Respondents indicated it is important for smart-home residents to meet remote staff, which would make the technology appear less invasive. It may be possible for clients, and their families and caregivers, to visit the service providers' remote monitoring center and meet remote staff in person. Staff can use this opportunity to demonstrate how the technology works and provide further reassurances about data privacy and storage. Wilkowska et al. (2015) reported that privacy

Table 7 Mean concern rating scores regarding each piece of technology for both the low- and high-concern groups, *p* values, and effect sizes

Technology	Mean concern rating (low-concern group)	Mean concern rating (high-concern group)	*p* value	Effect size (Cohen's *d*)
Video cameras placed in common living areas	1.97	2.78	<.05	0.93
Video cameras overlooking resident bedroom entrances	2.41	3.21	<.05	0.87
Video cameras overlooking resident bathroom entrances	2.49	3.32	<.05	0.95
Motion sensors located throughout the home that alert remote staff when triggered	1.67	2.48	<.05	0.90
A device that allows remote staff to switch appliances off remotely	1.53	2.05	<.05	0.54
Pressure mats placed on couches, beds, and certain parts of the floor that alert remote staff when residents stand, sit, or lie down on them	1.76	2.51	<.05	0.79
Devices attached to doors and windows that alert remote staff when a door or window has been opened or closed	1.53	2.22	<.05	0.78
Intercoms that allow remote staff to contact residents at any time	1.55	2.27	<.05	0.81
Cellphones and telephones on which remote staff can call residents at any time	1.35	1.89	<.05	0.62

concerns decreased when participants had the opportunity to view and interact with technology within a smart-home demonstration laboratory. Moreover, Brewer et al. (2010) suggested clients see the faces of remote staff when they communicate via technology. Smart homes can be equipped with videoconferencing software that allows remote staff to communicate with clients face-to-face; however, service providers should ensure that videoconferencing software is compliant with federal regulations. Thus, it appears that service providers can take an active approach when addressing privacy concerns. Moreover, we believe the role of remote staff should entail more than simply monitoring information and providing assistance when required; emphasis should be placed on building positive rapport and a meaningful relationship with clients. Service providers may also reduce privacy concerns by minimizing remote staff turnover given that it may be difficult for clients to establish positive rapport with remote staff if turnover rates are high.

The distribution of responses across concern ratings regarding client privacy was approximately the same when comparing smart homes with service models where staff are continuously present within the home. These results are similar to those of Brewer et al. (2010), who found that participants perceived the telecare service model to be as private as having staff continuously present within the home.

Not surprisingly, respondents identified video cameras overlooking bedroom and bathroom entrances as the technology that was the most concerning. Video cameras have been identified as a source of concern in previous studies (e.g., Brewer et al., 2010; Niemeijer et al., 2015). However, we found that concern ratings were lower when video cameras were located in common living areas. Supplementary analyses involving respondents with and without a family member with a disability produced similar results. It appears that privacy concerns regarding the use of video cameras are influenced by their relative location within the home.

The results from the supplemental analyses indicated a relation between how respondents rated their levels of concern about privacy within a smart home and how they rated their levels of concern about each individual piece of technology. On average, respondents who have high levels of concerns about privacy with technology are likely to also have high levels of concern about privacy with smart homes. The surprising result from the analysis was not that the high- and low-concern groups differed with respect to their levels of concern with the use of video cameras, but that they also differed significantly across all sensor- and communication-based technology. That is, the high-concern group reported higher levels of concern for *all* pieces of technology—not just cameras—relative to the low-concern group. We are unable to reach any immediate conclusions about possible reasons for why the two groups rated their levels of concern with the technology so differently.

The results from the supplemental analyses could have implications for how service providers market their service model to potential clients and their families and caregivers. We encourage service providers to emphasize client privacy and data storage. Service providers should also emphasize that the role of remote staff entails building positive relationships with clients in addition to monitoring information captured by the technology.

The study has limitations that warrant further discussion. A small number of respondents—relative to the number of agencies we contacted to distribute the survey—completed the survey, which limits the generality of our results. The diversity within the sample across all demographic variables somewhat mitigates this limitation. We may have been too conservative with our inclusionary criteria, which resulted in the loss of data. Data were excluded if participants did not complete all sections of the survey. The survey was arranged so that participants could only advance between the different sections of the survey if all questions within a section were answered, which may have led to participants not completing the survey if they were unable or unwilling to answer a question (or questions) within a section. Future studies may consider adjusting this requirement.

Additionally, the question that listed the different types of residential service models is not exhaustive and thereby not representative of all available services or service providers. The survey may not have captured all aspects of residential services that occasion concerns about client privacy, and we did not operationally define the term *privacy*; thus, respondents answered survey questions based on their own subjective interpretation of the term. Chung et al. (2016) provides several examples of operational definitions for the term *privacy*. We also had a limited number of responses from people who identified themselves as having a disability. We also did not collect information on their prior experiences or exposure to smart homes.

Despite the limitations of the study, our data add to a small body of literature investigating the privacy concerns of various stakeholders when using smart homes to provide services to individuals with disabilities. Such studies are important because the results have the potential to help service providers develop strategies to effectively and efficiently address these concerns. Based on the findings from this study, we provided several suggestions regarding the use of technology in such a way that promotes and protects client privacy, as well as how remote staff can assist in the process of ensuring client privacy.

Implications for Practice

- The personal privacy of individuals with disabilities receiving long-term services is an important issue for survey respondents.
- The secure and private storage of data captured by technology is extremely important when providing services using technology.
- Technology may appear less invasive if clients and their families and caregivers have the opportunity to meet remote staff either remotely or in person.
- The acceptability of technology-based service models may increase by addressing concerns regarding privacy.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

Appendix

Table 8 Summary of main suggestions

1. Consider the privacy of clients receiving long-term residential services:
   - The personal privacy of service recipients is an important issue for survey respondents.
2. Ensure the secure storage of data captured by smart-home technology:
   - Ensure data storage systems are compliant with U.S. federal law.
   - Only share data with appropriate individuals and in a way that respects client dignity.
   - Ensure safety and security of any hardware devices used to store data.
3. Arrange for clients and their families and caregivers to meet remote staff:
   - Clients and their families and caregivers should meet remote staff either in person at the monitoring center or remotely via videoconferencing.
   - Consider equipping smart homes with videoconferencing software that complies with U.S. federal regulations so that clients and remote staff can see each other's faces when communicating.
4. When marketing services involving smart-home technology, place emphasis on client privacy and data storage and the role of remote staff (monitoring information and building positive relationships with clients).

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