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Assessing Technology Needs for Residential Autonomy: Considering Individual and Environmental Context

Évaluation des besoins technologiques pour l'autonomie résidentielle : prise en compte du contexte individuel et environnemental

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Abstract

Residential autonomy poses a challenge for individuals with intellectual disability (ID; Carey et al., 2022), autism spectrum disorder (ASD; Longuépée et al., 2019) or physical disability (PD; Kingsnorth et al., 2015). However, living in autonomous housing would enhance the well-being of individuals with disabilities and their relatives (INESSS, 2019). The aim of this qualitative study is to identify barriers, strategies and needs related to residential autonomy, as well as collected suggestions for assistive technology tools. For this qualitative research, five individuals with disability, three relatives and 19 care providers and managers were asked about the main challenges, strategies, and needs observed in the activities of daily living (ADLs), and instrumental activities of daily living (IADLs), including transportation, emotional management, safety, and environmental control. The results of this first phase allow the co-development of technological tools that will support individual autonomy, in addition to increasing their social involvement in partnership with field experts.

Résumé

L'autonomie résidentielle représente un défi pour les personnes atteintes d'une déficience intellectuelle (Carey et al., 2022), d'un trouble du spectre de

l'autisme (Longuépée et al., 2019) ou d'une déficience physique (Kingsnorth et al., 2015). Cependant, résider dans des habitations autonomes pourrait augmenter le bien-être des individus et de leurs proches (INESSS, 2019). Cette étude qualitative a pour objectif de décrire les obstacles, les stratégies et les besoins relatifs à l'autonomie résidentielle, ainsi que d'obtenir des suggestions concernant les outils d'assistance technologique à développer pour promouvoir l'autonomie. Cinq individus en situation de handicap, trois proches aidants et 19 intervenants et gestionnaires ont été consultés pour fournir des informations sur les obstacles, les stratégies et les besoins observés dans les activités de la vie quotidienne, dont l'utilisation des transports, la gestion émotionnelle, la sécurité et le contrôle de l'environnement. Les résultats de cette première phase permettent le co-développement d'outils technologiques soutenant l'autonomie et la participation sociale en partenariat des experts.

Mots-clés : Autonomie résidentielle, Trouble du spectre de l'autisme, déficience intellectuelle, déficience physique, technologie d'assistance

Introduction

According to the report by *Protecteur du citoyen* (2020), access to suitable housing is a growing concern for individuals with disabilities. While member countries of the Organization for Economic Co-operation and Development report that, on average, 1.2% to 3% of their gross domestic product is allocated to disability programs (World Health Organization, 2011), individuals with physical disabilities (PD), autism spectrum disorder (ASD) or intellectual disabilities (ID) continue to face obstacles to residential autonomy (Carey et al., 2022; Kingsnorth et al., 2015; Longuépée et al., 2019). Residential autonomy has been linked to enhanced quality of life (INESSS, 2019). These individuals often rely on their families for housing (Billsted et al., 2011), which results in a financial and emotional investment by family members who provide care (Dudley & Emery, 2014; Karasavvidis et al., 2011).

A study conducted in Australia among individuals with PD indicates that lack of adapted housing contributes to their dependence or drives them to unsuitable institutional settings (Saugeres, 2011). These situations often reinforce isolation and can lead to challenging living conditions. The phenomenon of residential dependency among individuals with ID can largely be attributed to the financial burden of the service costs, compounded by low income and limited resource availability (Crawford, 2008). For individuals with ASD, residential dependency is primarily explained by the difficulty in finding accommodations that meet their individual needs (Lauzon, 2019) and that do not consider the optimization of their autonomy (INESSS, 2019).

The Human Development Model – Disability Creation Process (HDM-DCP; RIPPH, 2023), suggests that disability situation is influenced by personal circumstances, individual factors, and environmental factors, and offers understanding of barriers to residential autonomy. The idea of autonomy is constantly evolving and depends on an individual’s situation. For instance, van Loon et al. (2021) suggest that living in a residential setting can alter autonomy, while Morgan and Brazda’s (2013) vision of autonomy includes collaboration with teams and family to make decisions. Autonomy is a factor to consider in an environment with other residents and

professionals, while maintaining the perspective that each individual is unique and should be at the forefront of decision-making (van Loon et al., 2021). To support individuals with ASD, ID or PD in living independently in a safe environment, multiple resources are required. These individuals benefit from regular follow-up and genuine personal investment (Cullinan et al., 2011).

As current housing models are not optimal (Office des personnes handicapées du Québec [OPHQ], 2020), the use of assistive technology is pertinent. Assistive technology is defined as tools aimed to ensure the autonomy of people in their residential environment by promoting their social participation and decreasing the demands to family members and the health care system (Bouchard et al., 2017). The rate of development of assistive technologies is rapidly increasing, especially those focused on elders' well-being. While Canada has been recognized as one of the worldwide leaders in assistive technology for elders (AGE-WELL, 2019; AAL-Europe, 2019), it is essential to focus on populations with ID, PD, and ASD, as the challenges of accessing adapted housing for these populations are worsening (Protecteur du citoyen, 2020). For these populations, developing and implementing tools alone is insufficient. Indeed, the needs and preferences of the population for whom assistive technologies are designed should be considered prior to implementation (Ramsten et al., 2020; Batorowizc et al., 2016; Queirós et al., 2015). Hence, it is essential to identify the barriers, strategies, and needs related to the residential autonomy of people with PD, ASD or ID before developing tools for these individuals.

This qualitative study represents the initial phase of a series of collaborative studies conducted with the CIUSSS of Saguenay–Lac-Saint-Jean and a community organization (*Les Habitations du Parc*). The latter refers to an apartment complex for diverse populations, including individuals with ID, ASD, or PD, who could benefit from the development of technology-based solutions. These solutions will be developed collaboratively with the residents, ensuring a personalized approach. The primary objective of this phase of the research is to gather insights into the factors that facilitate or hinder residential autonomy by consulting individuals, their families, care providers, and managers. The second objective is to understand the residents' expectations regarding the role of technology in supporting their residential autonomy.

Materials and Methods

Design study

The study is based on a qualitative design, to allow the integration of participants' experiences into the research (participatory action research based on changes in the community; Creswell et al., 2007). Qualitative studies are particularly relevant in the context of medical research when they aim to directly obtain information from healthcare professionals and individuals (Neergaard et al., 2009), thereby reducing the researchers' influence on data (Chouinard et al., 2021).

Participant Characteristics

This study includes persons with ID, PD, and ASD, their relatives, care providers, and managers that work with them. The inclusion criteria for individuals with ID, ASD and PD are as follows: 1) be 18 years of age or older, 2) have a diagnosis of ID, ASD or PD, 3) have the ability to live independently with assistive technologies, as assessed by an independent committee of the CIUSSS, 4) require technological accommodation, 5) require mild to moderate intensity

rehabilitation services for individuals with ID or ASD, 6) be able to understand and answer questions. The inclusion criteria for relatives are as follows: 1) be 18 years old or older, 2) taking care of a person who meets the criteria described above, 3) not providing care as one's job. The inclusion criteria for ID, ASD and PD care providers and managers are: 1) be 18 years of age or older, 2) work as a care provider or a manager with individuals who have ID, ASD or PD. The characteristics of the participants selected based on the inclusion criteria are shown in Tables 1.1 and 1.2.

Procedure

This research was approved by the Ethics Review Boards of the Saguenay–Lac-Saint-Jean Integrated University Health and Social Services Centers. All participants provided written consent for the study.

Individuals with ID, PD and ASD, as well as their relatives, care providers, and clinical managers were recruited by program managers at CIUSSS of Saguenay–Lac-Saint-Jean. Prior to participation in an interview or focus group, all participants were provided with a socio-demographic questionnaire. This questionnaire was designed to collect information on age, sex, educational background, job title (with length of service), the individual or relative diagnosis, place of residence, and income.

Interviews and focus groups were conducted via videoconference or phone due to the pandemic (see Table 1.1 and 1.2). A semi-structured interview guide, adapted to each group, focused on obstacles and strategies for residential autonomy, and expectations toward assistive technology, was used with the participants (see Appendix 1). The customized questionnaires for each group of participants were developed collaboratively with a team from Université du Québec à Chicoutimi (UQAC), who have worked on several artificial intelligence projects to support individuals, as well as the CIUSSS and *Habitations du Parc* teams*,* who provided expertise on the project and individuals with disabilities.

Given the pandemic, the recruitment objective for individuals with disabilities had to be adjusted downward due to the need for remote interviews to be conducted via phone or videoconference. All participants with PD chose to conduct their interviews over the phone, which made conducting focus groups impossible. The participant with an ID preferred to be with a relative for their interview, partially for assistance with technology. The option of involving a relative in the interview had been discussed to enhance comfort for individuals with ID or ASD. However, a moment was taken with the individual alone to ask some questions, ensuring that the risk of contaminating the interview was minimized. In addition, this relative participated in an individual interview.

Online focus groups were conducted with care providers and managers. According to Moore et al. (2015), online focus groups have significant advantages for qualitative research as they facilitate rich exchanges by investigating the perspectives of all participants to uncover diverse interpretations.

Table 1.1

Characteristics of participants with, relative with or individuals working with people who have ID or ASD

Participants	Individual with ID	Relative of individual with ID	Individual with ASD	Relative of individual with ASD	Care providers	Managers
Type of Interviews: n						
Individual Interview		1	1	2		
Focus group	1 (with relative)				8	4
Variables						
Sexe: n (%)						
Female	1(100%)			1(50%)	7(87.5%)	3(75%)
Male		1(100%)	1(100%)	1(50%)	1(12.5%)	1(25%)
Age (years) : n						
20-35	1		1		3	
35-50					4	3
50-65		1		2	1	1
65 +						
Occupation (average years of service when data is available)						
Work placement program	1					
Entrepreneur		1				
Student			1			
Assistant director				1		
Stay-at-home parent				1		
Special needs educator					4 (11.5)	
Psychoeducational specialist					2 (2.5)	
Speech therapist					1 (9)	
Occupational therapist					1 (5)	
Rehabilitation leader						2 (2.25)

Clinical activities specialist	1 (11)
Childhood program manager	1 (10)

Table 1.2

Characteristics of participants with, relative with or individuals working with people who have PD

Participants	Individual with PD	Care providers	Managers
Type of Interviews: n			
Individual Interview	3		
Focus group		4	3
Variables			
Sexe: n (%)			
Female		4(100%)	2(67%)
Male	3(100%)		1(33%)
Age (years): n			
20-35	1	3	
35-50		4	3
50-65		1	1
65 +			
Occupation (average years of service)			
Unemployed	3		
Nutritionist		1(13)	
Social worker		1(13)	
Clinical nurse		1(2.5)	
Occupational therapist		1(21)	
Home care manager			1(10)
Rehabilitation manager			1(5)
Coordinator			1(2)

Data Analysis

Interviews were transcribed and qualitatively analyzed using NVivo software (Version 12). The data analysis method is based on the article by Chouinard et al. (2021). A mixed thematic

analysis approach (Miles et al., 2014) was used to identify line-by-line codes and sub-codes for the interview topics. A data triangulation process was conducted among the four participant groups by three researchers and two research assistants trained in qualitative studies. This process identified converging and diverging themes. The data were then categorized into previously identified themes and organized into tables. Finally, the data were interpreted and explained. Each step was validated by each member of the research team to ensure inter-rater agreement.

Results

Participants

In the interviewed sample, there were more individuals with PD (3) involved in interviews compared to those with ID (1) and ASD (1). The average age of the individuals with a disability was 42.8 years. The sample was predominantly male (80%). Most care providers were females (84.2%), while most relatives were male (67%). PD care providers had the highest average experience (12.4 years), while managers working with this group had the lowest average experience (5.7 years). ID and ASD care providers had an average tenure of 7.9 years, while managers had been in their positions for an average of 6.4 years.

Residential Autonomy

The main obstacles to residential autonomy (see Table 2.1) for activities of daily living (ADLs) were related to hygiene for all populations. Regarding instrumental activities of daily living (IADLs), financial resources were found to pose different challenges depending on the individual's disability. People with ID or ASD were reported to face financial management obstacles, while individuals with PD struggle with the cost of equipment. Obstacles such as memorization, organization, planning, and emotional management were particularly prominent for individuals with ID or ASD. Mental flexibility was often identified as an issue for residential autonomy among people with ASD. Safety risks identified for individuals with disabilities include fraud, abuse, falls, difficulties in managing social network interactions, and misuses of appliances.

Table 2.1

Obstacles to Residential Autonomy

Obstacles	Group	Specific Impacts
Lack of resources	All group	Insufficient staff and limited accessibility to services 24/7
	ID/ASD	Difficulty expressing their needs to family or to professionals
	PD	Fear of inconveniencing others
		Waiting times for programs access
IADL	ID/ASD	Difficulty remembering the steps to prepare a meal
		Difficulty checking for expired food in the refrigerator

		Forgetting to turn off the stove
		Challenges with housekeeping tasks
		Rigid adherence to housekeeping routines
		Difficulty or reluctance to take medication
		Budgeting difficulty due to limited numeracy skills
		Challenges using ATMs, credit cards and bank accounts
		Requiring appointment by phone for transportations
		Planning issue for transportations schedule
		Forgetting to set the alarm clock
		Misplacing objects due to organizing and planning difficulties
	PD	Difficulty in accessing transports, especially in adverse weather conditions
		High cost of assistive devices
		Lack of support for carrying shopping bags
		Challenge with grocery shopping
ADL	PD	Reduced mobility due to difficulties with transfers
		Difficulty entering the shower or bath
	ID/ASD	Reminders for personal hygiene tasks and steps
		Security concerns with water temperature during personal hygiene tasks
	All group	Risk of choking on food
		Tendency towards unhealthy eating habits and low physical activity leading to overweight
Cognition	ID/ASD	Cognitive perseverations
		Limited problem-solving strategies
Emotion	ID/ASD	Risk of panic and crisis

Participants acknowledged the existence of several strategies to enable individuals with disability to live at home (see Table 2.2). For many participants, ADLs require assistance from family members. Individuals with ID or ASD also identified the use of strategies based on pictograms and preset sequences on electronic tablets. Emotional management was reported to be impacted by ASD, so care providers reported teaching anxiety management and relaxation strategies to individuals with ASD and their family. Subscribing to home support community services was a commonly identified strategy for IADL and ADL completion. Participants with disability also reported use of demonstration tools that provide instructions in an adapted manner.

Table 2.2

Strategies for Residential Autonomy

Categories	Groups	Strategies
ADL	All group	Human assistance
		Voice assistance tools
		Accessible adapted transport
	ID/ASD	Pictograms
		Establishment of routines
		Set reminders on cell phones
	PD	Thickening agent to reduce choking risk
		Wheelchair, scooter, walker for mobility
Communication	All group	Speech synthesis
		Voice recognition
		Video conference software
	ID/ASD	Lists to associate names, photos, and phone numbers
Emotional	ID/ASD	Consistency/Routine
Management		Relaxation strategies
		Social strategies
		Taking breaks/Withdrawing
		Walking
		Strategy reminder sheets
IADL	ID/ASD	Subscribing to home support community services
		Clear instructions
		Demonstration tools
		Budget management steps
		Timer
		Sequence on electronic tablet
		Lists
		Calendar

Expectations and Needs

Participants expressed the need for technological adaptations in communication to facilitate connection with others. Controlling the environment and ensuring safety were identified as needs to promote residential autonomy. Specifically, care providers and relatives of individuals with ASD or ID reported the need for support in preventing item loss, managing household

appliances, and assisting with anxiety management and hygiene, while respecting privacy. Care providers emphasized the importance of extensive trials and training to develop an individual's ability to use assistive technologies daily. For individuals with PD, safety was identified as a priority, followed by quality of life and independence.

A participant summarized a shared perspective by emphasizing the importance of a "social participation and autonomy enhancement perspective, rather than a control perspective", highlighting the priority of empowering individuals over monitoring them.

Utilization of Assistive Technology

Several suggestions were made for the development of new assistive technologies (see Table 3). Examples include creating pictograms, utilizing voice assistants, and adapted online ordering tools. Developing tools such as schedules and voice reminders could aid organization and planning. Safety-related proposals included such examples as smart insoles with GPS, a sensor designed to automatically shut off water to prevent flooding and fall detection sensors.

Table 3

Suggestion for Assistive Technology

Categories	Suggestions
Communication	Pictograms for expressing needs on a tablet
	Choice of preset words/sentences
	Scenarios for learning purposes
	Pre-recorded messages
	Speech synthesis
	Adapted online ordering tools
	Sound amplifier
	Videos for providing examples
Environmental control	Voice control for water, curtains, lighting, and heating
	Bracelets for opening doors
	Artificial intelligence for detecting and assisting in resolving problematic situations
	Door codes
	Motion detection for opening sink and garbage can
	Kitchen timer
	Automatic closing of the stove
Entertainment	Aids for using leisure tools
	Activity planning assistance

Emotional management	Visual tools
	Automatic assistant for managing anxiety symptoms
	Electronic mood tracking
	Robot for managing social relationship difficulties
Organization and planning	Visual schedules
	Technology-assisted appointment scheduling
	Electronic to-do lists
	Voice reminders
	Verbal calendar
	Automatic transportation reservation
	Tracking chip for locating objects
Security	Smart insoles with GPS
	Water level stops
	Security sensors (only in case of problems)
	Emergency services button
IADL	Adapted meal preparation steps on applications
	Audible timer for the oven
	Voice control for the oven and microwave
	Pre-programmed toaster
	Automatic cleaning toilet
	Medication reminder
	Automatic opening of the multi-dose medication carts (PD)
ADL	Tooth brushing aid (PD)

Discussion

Interviews with individuals with disabilities, their relatives, care providers, and managers have confirmed interest in developing assistive technology. This interest is particularly prominent in a context where the lack of human resources is cited as a major obstacle to residential autonomy, which is a challenge faced by all targeted populations of the project. Multiple studies, including those by Koester et al. (2007) and Crawford (2008) identified a shortage of professionals to support individuals with PD, ASD or ID. The study by Koester et al. (2007) incorporates technology assistance to facilitate the implementation of a keyboard configuration tool designed to support individuals with PD. Moreover, these authors report that people with disabilities are often hesitant to request assistance due to the fear of being perceived as annoying (Crawford, 2008; Koester et al., 2007). One issue brought forward in the findings is the extent of testing and training. Researchers should be mindful of this when working with this population. They need to

ensure that the implementation process is suitable for their needs, even if it requires taking the lead in initiating the discussion.

The uniqueness of each individual with disabilities was the main priority to ensure the implementation of technological assistance. Care providers identified the involvement of individuals with disabilities as a primary aspect to consider when developing tools. Furthermore, this development should consider the capacities for developing autonomy and strive to achieve it, without compensating for elements that may not cause problems. Hence, the relevance of truly focusing on the individual. Additionally, the individuals with disabilities and their relatives appreciated being consulted about the needs and characteristics of the population. This process can foster decision-making autonomy and increase the sense of control experienced while living with disabilities (van Loon et al., 2021). This aligns with the studies conducted by Ramsten et al. (2020) and Batorowizc et al. (2016), highlighting the importance of considering the needs and preferences of the population with ID regarding assistive technologies before proceeding with their implementation, as well as their significance in strengthening the social bond with the family. Therefore, one of the potential obstacles to the implementation of technology might be the lack of confidence among the individuals and their relatives towards these assistive technologies. The study by Nicholson et al. (2013) specifically addresses this aspect and emphasizes the importance of building trust with relatives, which was done in this first phase of the study based on the recommendations of Clemensen et al. (2007) and Israel et al. (2001). These authors advocate for the involvement of all actors throughout the design and experimentation process to develop interactions between individuals with disabilities and designers.

Several meetings were held with individuals with disabilities, their relatives, care providers, and managers following the analysis of the results in order to present the Findings. This sharing facilitated the exchange of ideas and the collection of feedback from individuals who will be directly impacted by the outcomes of the research. With the overall approval of the results, the research team recognized the relevance of involving individuals, their family members, and professionals and this process will continue in the subsequent phases of the research, aligning with the input provided by the participants.

Limits

COVID-19 significantly impacted the most vulnerable groups (Laurencin & McClinton, 2020). Since the study was conducted during the pandemic, the context might have influenced some participants' answers. Additionally, the interviews were conducted via videoconference or phone, which may have affected participants' behavior and responses.

Another limitation is that the distribution of family caregivers does not include relatives of people with PD, potentially resulting in underestimated certain aspects of their lives. These relatives may be less involved due to age and isolation. However, this study addressed this limitation by including more participants with PD.

Future Development

Based on the findings, a second phase has begun for the development of technologies in collaboration with the targeted individuals. This phase involves the development of tools that

will be implemented in the apartment to support individuals with disabilities in their autonomy and enhance their social involvement.

Key Message

People with disabilities: Even if there are difficulties regarding your home and the autonomy you could develop there, there are solutions. It is important that these solutions be discussed with you, your family, and your professionals so that they correspond to your needs.

Professionals: The main barriers for individuals with disabilities who require assistance are related to activities of daily living and instrumental activities of daily living, such as finances, eating, hygiene, and housework. Study participants expect these challenges to be addressed with assistive technology tools. However, it is crucial that these tools promote autonomy and not control.

Message clé

Personnes avec un handicap : Même s'il y a des obstacles concernant votre domicile et l'autonomie que vous pourriez y développer, il existe des solutions. Il est important que ces solutions soient discutées avec vous, votre famille et vos professionnels afin qu'elles correspondent à vos besoins.

Professionnels : Les principaux obstacles à l'autonomie résidentielle pour les individus ayant un handicap sont liés aux activités de la vie quotidienne et aux activités instrumentales de la vie quotidienne, comme les finances, l'alimentation, l'hygiène, le ménage. Les participants s'attendent que ces défis soient adressés grâce aux outils technologiques, mais ceux-ci doivent favoriser l'autonomie et non contrôler.

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Appendix I

Co-design, deployment, and evaluation of innovative technological solutions within multi-client living environments: Needs Assessment (Phase 1).

[English translation of the original French guide]

Interview Guide for Focus Group with Managers and Care Providers (ID/ASD/PD)

Introduction

As mentioned, today's meeting focuses on individuals with (ID/PD/ASD) who can benefit from the design of innovative technological solutions within an adapted multi-client environment. There are no right or wrong answers to the questions I will be asking. As you are the expert of your own experience, I want to know your perception, and I am interested in your personal responses. Throughout the meeting, feel free to interrupt me and ask questions. Do you have any questions? Do you understand what we will be discussing? Are you ready to begin?

Q.1 Facilitators and Obstacles for Residential Autonomy for Individuals with (ID/ASD/PD)

Q1.1 Can you describe the obstacles you encounter regarding the residential autonomy of this population? Can you describe the obstacles they face in performing their daily activities?

- Daily living activities (e.g., eating, medication management, personal care)
- Mobility?
- Communication?
- Cognitive abilities?
- Household tasks?
- Others?

Q1.2 What strategies have you tried to maintain this population at home? And what are the impacts of these strategies?

Q.2 Expectations Towards Technology to Support Residential Autonomy

Q2.1 In your opinion, how could technology contribute to maintaining individuals with (ID/ASD/PD) at home?

- Daily activities (e.g., eating, medication management, personal care)
- Mobility?
- Communication?
- Cognitive abilities?
- Household tasks?
- Other?

Q2.2 What, in your opinion, are the obstacles to the use of technology by this population?

Q2.3 What factors, in your opinion, would facilitate the use of technology by this population?

Q2.4 According to you, what are the priority needs that should be addressed with technology?

Q2.5 What would be the main implementation challenges (aside from those related to the individual) of these technologies?

Conclusion

In conclusion, would you like to add anything else to our discussion?

Do you have any additional questions?