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Challenges in the Completion of Daily Living Activities in Residential Settings

Abstract

For people with intellectual disabilities, access to autonomous residential settings means access to independence and self-reliance. Unfortunately, access is hampered by the lack of skills and competencies required to carry out certain daily living activities. To date, little information is available concerning the challenges faced by people with intellectual disabilities in the performance of these activities. The goal of this study is to make an initial assessment of the needs and challenges faced by these individuals. This qualitative research relies on a triangulation of data from people with intellectual disabilities, service providers, and family members. A total of 56 people participated in 11 discussion groups. Through an analytical questioning analysis, we were able to categorize the challenges into eight spheres of activity.

Supporting residential integration is currently a priority in the field of intellectual disability (ID) (Ministère de la Santé et des Services sociaux [MSSS – Québec Ministry of Health and Social Services], 2003). Indeed, access to housing is an important component underlying social integration and participation (MSSS, 2001); it is seen as “an indicator of independence, self-reliance and normality” (Morin, Robert, & Dorvil, 2001, p. 92). However, residential integration requires a thorough understanding of individuals’ needs and skills related to the accomplishment of their daily living activities (DLAs).

Home Support and the Development of Innovative Residential Models

In the province of Québec, these concerns have led to the implementation of government policies that direct the actions to be carried out in connection with home support (MSSS, 2004). To this end, public, para-public and community organizations are responsible for promoting the adaptation of home settings and for improving the opportunities offered to individuals with ID (MSSS, 2001). These organizations also have the statutory obligation to provide these individuals with the intervention and information tools that will bring about their academic, professional and social integration. In addition, social integration remains a cornerstone of the organization of health and social services provided to them, and all decisions regarding the determination of needs and the organization of these services must take the individuals themselves as a starting point (MSSS, 2001).

The development of innovative residential models could have major impacts on people with ID and act as a protective fac-

tor. In recent years, Québec government authorities have implemented a home support policy to guide the implementation of related policies (MSSS, 2004). For people with ID, this home support must compensate for functional limitations and promote the development of abilities (MSSS, 2001). It must also encourage self-reliance and independence. Since the implementation of this policy, there has been a diversification of housing options available to this clientele. Among the solutions proposed, access to autonomous and supervised apartments seems to have a promising future (Pedlar, Hutchison, Arai, & Dunn, 2000). Early studies show the popularity of this residential model as well as its positive impacts on the social participation of people with ID (Heller, Miller, & Factor, 1999; Robertson et al., 2001; Stancliffe & Abery, 1997). These environments would also have positive impacts on self-determination and quality of life (Haelewyck & Nader-Grosbois, 2004). More specifically, the various dimensions of self-determination on which impacts have been identified are behavioral autonomy and psychological empowerment (Ringsby & Jansson, 2002 as cited in Hällgren & Kottorp, 2005; Morin et al., 2001). However, the effects on self-regulation and self-actualization components seem more difficult to quantify (Hällgren & Kottorp, 2005; Lovett & Haring, 1989).

Unfortunately, access to housing is seriously compromised for people with ID due to the lack of skills and aptitudes required to carry out certain tasks. In short, to integrate into these settings, these people must develop a number of essential functional and adaptive skills (Morin et al., 2001), as well as learn to use technologies that are directly integrated into their residential settings.

Development and Expression of Functional and Adaptive Skills

The home environment is a space that allows the expression of behavioral autonomy (Morin et al., 2001). Specifically for people with ID, home is seen as a place where they can develop new functional skills (cleaning, preparing meals, etc.), and thus supports the principle of self-determination. In addition, the performance of tasks in a residential setting encourages individuals' participation and sense of

well-being (Wattudal, 1998 as cited in Hällgren & Kottorp, 2005). Access to residential settings is still a challenge not only for people with ID, but also for service providers, family members, and researchers interested in the subject. Indeed, the assessment of abilities, as well as the implementation of interventions, should be carried out from the perspective of a pursuit for autonomy (Lussier-Desrochers, Lachapelle, Consel, & Lavergne, 2010). Analyzing the situation and applying the appropriate technology will support not only the performance of DLAs but also the learning of new skills. Therefore, the potential removal of technology from the person's living environment could be the ultimate goal to achieve in the course of an intervention, which would be in itself an indicator that the person has acquired a certain level of autonomy. Conversely, this objective could never be reached by people who were losing their autonomy and who would thus have a growing need for technological support. Finally, all these elements are modulated by the severity of the disability, which is in itself a fundamental variable, which will greatly influence the level of assistance required to ensure adequate support in carrying out DLAs (OPHQ, 2007).

Access to housing thus underlies the expression of a series of skills related to DLAs such as preparing meals, maintaining a safe environment, taking prescribed medication, cleaning the house, managing a budget, managing time, and looking after personal hygiene and health (Corbeil, Marcotte, & Trépanier, 2009). In recent years, research has focused primarily on motor conditions that are prerequisites to the accomplishment of DLAs (Chen et al., 2010; Kottorp, Bernspang, & Fisher, 2003), and on executive functions (planning, sequencing, and attention control) involved in accomplishing these tasks (Vaughan & Giovanello, 2010; Wherton & Monk, 2008). Analyzing these tasks helps to identify the difficulties faced by individuals when performing DLAs and allows us to develop types of interventions that will specifically target these problems (Hällgren & Kottorp, 2005). These analyses are even more important for an aging clientele, who needs interventions that will counterbalance this functional loss (Chen et al., 2010).

At this time, little information is available concerning the challenges faced in residential

settings by people with ID in the performance of their DLAs. However, the study by Proulx, Dumais, and Vaillancourt (2007) provides some avenues worth exploring. Indeed, these authors conducted a study evaluating various aspects of apartment living for disabled people. Note that the sample also included people with ID. The results show that preparing a full meal, managing the unexpected, planning a budget, and making minor repairs cause more difficulties for people with ID living in an apartment, and therefore require more assistance (OPHQ, 2007). A study by Boisvert, Bonin, Boutin, and Lachapelle (1995), conducted among aging people with ID, comes to similar conclusions. The results also show that these individuals are relatively autonomous in performing certain DLAs, such as personal hygiene and dressing. Finally, it is important to note the concerns of the people close to these individuals (service providers and family members) regarding all safety-related aspects of residential settings (Canada Mortgage and Housing Corporation - CMHC, 2006). In this regard, Mercier (2005) mentions that the risks of victimization (e.g., breaches of domicile and burglaries) are 13 times higher for people with ID. Combined with other risks associated with living in residential settings (e.g., fire, flood and injury), safety-related aspects appear to be key elements to consider when setting up autonomous residential models for people with ID (Boucher, 2010).

Recently, researchers in the field of ID intervention and computer science have established partnerships to develop technologies specifically for people with ID (Lussier-Desrochers, 2012; Canada Newswire, 2012). Moreover, studies show that technology can help them carry out DLAs (Banda, Dogoe, & Matuszyny, 2011; Hammond, Whatley, Ayres, & Gast, 2010; Parsons, Daniels, Porter, & Robertson, 2006). However, successful technological intervention should be suited to users' needs and abilities (Lussier-Desrochers et al., 2010). Although some studies address the challenges faced by physically disabled people in carrying out DLAs, few specifically targeted people with ID in residential settings. Yet, this information is essential for computer scientists and engineers designing these new assistive technologies, as it enables them to create decision-making trees that help guide software programming and

testing (Lapointe, Bouchard, Bouchard, Potvin, & Bououane, 2012). As a result, these technologies may be used more efficiently in direct interventions in residential settings.

Objectives

This research project thus aims to contribute to a primary assessment of residential setting needs of people with ID. More specifically, the project deals with the challenges they face in carrying out DLAs. Describing these elements will pave the way for the development of technological solutions adapted to specific DLAs.

Method

Since this area of research is still poorly documented, using a non-experimental descriptive research design is preferred. Using this method will enable us to carry out a detailed analysis of the DLAs of people with ID.

Participants

To achieve the most complete picture possible of the situation faced by people with ID in their performance of DLAs, we favoured a triangulation of perspectives. Three groups of participants were therefore approached: people with ID, family members, and formal caregivers from three CRDITEDs (Intellectual Disability and Pervasive Development Disorder Rehabilitation Centres). To begin, the professional services, quality and research managers of the CRDITEDs were informed of the research goals and inclusion criteria, which included: (1) caregivers had to be working directly with people with ID in the field of residential integration; (2) family members had to be receiving rehabilitation services and be living with a person with an ID; (3) people with ID had to present a mild or moderate ID; and (4) they also had to be able to share their experience, perform household activities and live in an independent setting (apartment or room pension). The managers then recruited the participants based on these criteria and provided contact information to the researcher.

A total of twenty adults with mild or moderate ID participated in the study. At the time of the group discussions, they were all receiving

services from the CRDITED in their respective region. Among these participants, 17 were living in autonomous or supervised apartments or in room-and-board situations. The three others were considering moving into an apartment in the short or medium term. In addition, 23 caregivers agreed to take part in the study. The latter were working with people living in autonomous or supervised apartments. Finally, 11 family members of people with ID agreed to answer the researcher's questions. Members of this last group all had a family member with an ID living in an apartment or planning to do so in the near future.

Data Collection

The semi-structured interview guide used in this study is an adapted version of the inventory of apartment living skills created by the Groupe de recherche et d'étude en déficience du développement (Group for Research and Study in Developmental Disability) (Corbeil, 2009). The skills assessment inventory, which addresses difficulties in carrying out DLAs, is used to evaluate individuals' residential support needs. We added a question to explore improvements that could be made to support task achievement in a residential setting. A personalized discussion group framework was applied for participant subgroups. Each theme was addressed using sub-questions. In order to encourage exchanges during group discussions with people with ID, role-playing was used.

The various participant subgroups were met in the context of semi-structured group discussions, five of which were conducted with the individuals with ID, three with the caregivers, and three with the family members. The interviewers were trained by Boucher (2010), who had conducted focus groups as part of her master's program. Table 1 shows the distribution of participants and groups by CRDITED location.

Analysis

The corpus of verbatim data collected was analyzed through analytical questioning (Paillé & Mucchielli, 2008). An exploratory review of the data was first performed using an initial investigative framework that sought to answer two questions: (1) Which DLAs require the most assistance for people with ID? (2) What are the main concerns with respect to the performance of DLAs? This operation allowed us to refine the elements of the investigative framework according to the different DLA categories and led to a consolidation review. All the data in the corpus were reviewed in light of the new investigative framework. Then, a final validation review ensured the comprehensiveness of the analysis performed. These operations were carried out using QSR NVivo 8 software.

Results

Since the analysis shows agreement in the participants' point of view, the results will be pre-

Table 1. Distribution of the Participants and Groups by CRDITED Location

	<i>Saguenay- Lac-St-Jean</i>	<i>Québec City</i>	<i>Laval</i>	<i>Total</i>
Persons with ID				
Number of participants	10	3	7	20
Number of groups	2	1	2	5
Family members of persons with ID				
Number of participants	5	6	0	11
Number of groups	1	2	0	3
Service providers				
Number of participants	7	7	9	23
Number of groups	1	1	1	3

sented in groupings based on DLAs. However, the results section will include some points of view that are specific to each group of participants.

Food Preparation

Food preparation is one of the DLAs that give people with ID the most difficulty. First, using a stove and oven can be problematic, particularly when it comes to choosing the cooking temperature and time, as well as removing a hot dish from the oven. Other skills that people with ID may be lacking, include: opening cans, following the steps of a recipe and choosing the quantity of food to prepare. A lack of food variety is sometimes problematic, as well as food hygiene, particularly because of the difficulty in properly storing and preserving food and in recognizing spoiled food. Menu planning can also be difficult, and consequently, writing a complete grocery list, and prioritizing the items to purchase may be challenging.

Housekeeping

Housekeeping includes many tasks with various levels of complexity. Less frequently performed tasks, such as washing walls, washing windows, or vacuuming under heavy furniture seem to be the most problematic. Some tasks, without being complex, are sometimes forgotten by people with ID. These include washing mirrors, floors and bedding, as well as dusting. Other issues include choosing the right cleaning product in the right quantity, as well as noticing that it is time to change the trash bag and bringing the garbage out to the street at the right time. Performing housekeeping tasks in their entirety, that is to say, without overlooking a step, can also be challenging. For example, it is common for only a portion of the floor area to be swept. Hygiene during housework is sometimes a concern as well. For example, hand washing is sometimes neglected after certain tasks, such as washing the toilet bowl. In addition, pet owners sometimes have trouble performing certain tasks, such as cleaning the litter box. Finally, the frequency with which housekeeping tasks are performed can be a problem. Sometimes, it may be too high; however, a lack of regularity is often observed.

Budget

The budget is another priority area that may present numerous difficulties. Given that people with ID often have limited incomes, they must make economical consumer choices. However, frequent telephone or in-person solicitations may lead to impulse purchases, which have a significant impact on the budget. Furthermore, purchasing prepared food constitutes a major expense for these individuals. In addition, various banking transactions, including bill payments, present a challenge, and are frequently delegated to a third party.

Clothing

Some difficulties are encountered in putting together an outfit or in choosing clothes based on the weather, temperature, and season. With respect to clothing care, difficulties can be observed in the use of the washing machine, particularly with respect to the choice of wash cycle and water level. Moreover, some people occasionally choose to do a wash even if there are only a few dirty clothes. Conversely, others will wear their clothes for too long before washing them, or will wait until they have no fresh clothes at all to wear. Other difficulties that arise are related to sorting clothes and using the proper amount of detergent.

Health and Personal Hygiene

Taking medication accounts for the majority of the difficulties encountered. These include taking the right amount of prescribed medication at the correct frequency. For example, medication may be taken at the wrong time or simply forgotten. Sometimes, an excessive amount is then taken to compensate for the times it was forgotten. For occasional discomfort resulting from headaches, colds or nausea, many individuals know which medication to choose, but will not necessarily use the proper amount. Additionally, many do not know first-aid procedures for minor injuries.

In general, these individuals are able to tend to their personal hygiene, but not always at the proper frequency, particularly with respect to tooth brushing and nail trimming. At bath

time, using an adequate amount of water and checking the temperature can be problematic.

Safety of the Environment

Maintaining a safe environment is a major concern. For example, some individuals will forget to close and lock windows and doors when they leave their apartment. Many frequently forget their keys as well. Maintaining a proper temperature inside the apartment and realizing that it is too high or too low can be challenging. In the event of major malfunctions or emergencies such as power outages or water damage, many individuals have trouble responding appropriately. Furthermore, many will spontaneously open the door even if they do not know who their visitor is. Finally, the phone is an important element in apartment safety and, in some cases, its use should be simplified to accommodate these individuals.

Time Management

Managing time represents a certain number of challenges, such as planning certain appointments and remembering the time of the appointments. Some low-frequency appointments, such as the dentist, are more problematic. As a rule, organizing one's time to accomplish all the tasks necessary for apartment living, particularly with respect to housekeeping and food, can be difficult. In addition, some people have trouble occupying their free time.

Other Concerns in Relation to DLAs

Some concerns with respect to DLAs are common to several types of tasks. For example, the motivation to perform certain tasks may sometimes be lacking, and learning tasks can take long because of these individuals' cognitive characteristics. In addition, performing all the steps of a task in the correct order without stopping prematurely because of a distraction is a major concern. The rate at which tasks are performed is equally worrisome. In addition, reading skills are often deficient in these individuals, which can make it difficult to deal with the mail, as well as to use a calendar for schedule planning. Similarly, all tasks involving reading skills, such as following a recipe, choosing a

household product or taking medication appropriately, may be compromised.

Discussion

This study has enabled us to document the needs of people with ID with respect to carrying out their DLAs. The topic addressed is related to an important aspect associated with social participation, that is, access to housing. Up to now few studies have addressed the specific challenges faced by these individuals in their residential settings. And yet, this element is fundamental if we want to establish intervention tools tailored to their needs and abilities.

This study yielded a considerable amount of information about the tasks performed by individuals with ID in their residential settings. Further analysis of the results shows that food preparation and budget management are the most difficult tasks for these individuals. These findings are consistent with the results obtained in other studies (Boisvert et al., 1995; Proulx et al., 2007). On the one hand, with respect to food preparation, two factors influence the complexity of the task: the number of steps or operations involved and some aspects related to safety (turning off the oven, food safety, etc.). Therefore, food preparation tasks are inseparable from safety elements, and developing interventions combining both aspects appears to be important. On the other hand, the high level of abstraction involved in budget management appears to explain the difficulties faced by these individuals in connection with this aspect. These findings provide interesting guidelines that will help in the development of interventions designed to promote the self-determination of these individuals. As emphasized by Robertson et al. (2001), these interventions must focus on skill development, among other things. Moreover, the technologies available provide promising solutions for promoting skills development in these individuals and supporting them in carrying out tasks in residential settings. Based on the results obtained, it will be possible to determine precisely which currently available technologies can be integrated into the residential settings of these individuals to stimulate their self-determination.

By recording a variety of points of view, we were able to highlight specific concerns for

each category of participants interviewed. First, caregivers reported more concerns about the execution of the tasks themselves (being able to clean up, follow a recipe, do laundry, etc.), family members were more worried about the context in which the tasks were accomplished (safety, isolation, etc.), while the concerns of the people themselves were more closely related to improving their quality of life (being able to prepare a wider variety of meals, making house cleaning more pleasant, making life simpler, etc.). In addition, caregivers identified the greatest number of difficulties related to the performance of DLAs, followed by family members, and the individuals themselves. We also observed that many DLA categories involve a certain degree of subjectivity. This is precisely the case for apartment tidiness and variety of cooked meals. In regard to those aspects, caregivers and family members seem more demanding than the people with ID. Future studies should investigate the impact of this subjectivity aspect on residential integration.

These findings show the importance of involving persons with ID, families, and service providers in the development and implementation of interventions in residential settings. Unfortunately, skill evaluation tools for residential settings usually target a single category of respondents. Furthermore, there are obviously issues involving personal values associated with carrying out certain DLAs (frequency of personal hygiene, food variety, etc.). These often-overlooked issues are significant factors in channelling the support and interventions to be implemented. Few studies have examined this aspect, and it would be interesting to probe this dimension in future research.

Finally, it is interesting to note that, even if these people do not perform tasks with full autonomy (food preparation, housekeeping, etc.), many have developed adaptation mechanisms allowing them to meet their needs. For instance, many rely on home helpers for housekeeping. For many, this seems to be a positive element contributing to their quality of life. As a result, it can be seen as a legitimate choice made by the individual.

Conclusion

It is our hope that further exploration of this research topic will bring about the development of an innovative residential model promoting social participation and independence of individuals with ID.

Key Messages From This Article

People with disabilities: This work helps others to understand the challenges you face and how to help make things easier for you at home.

Professionals: A better understanding of the challenges faced daily by people with ID in residential settings can lead to successful interventions. These interventions will then promote these individuals' integration into residential settings. Our research shows that food preparation, housekeeping, budget, health, safety of the environment, and time management are challenging for these individuals. We also noted that many categories of daily living activities involve a certain degree of subjectivity.

Policymakers: The daily challenges faced by people with ID and the skills they need to develop must be considered in policies promoting integration into residential settings. This knowledge will contribute to successful interventions. It is our hope that this research will encourage the development of innovative residential settings suited to their needs and abilities.

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