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Research paper

Creating a rehabilitation living lab to optimize participation and inclusion for persons with physical disabilities☆

Création d'un laboratoire vivant en réadaptation pour optimiser la participation et l'inclusion des personnes avec déficiences physiques

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ARTICLE INFO

Article history:
Received 10 June 2013
Accepted 3 March 2014
Available online 14 June 2014

ABSTRACT

We present an on-going multidisciplinary and multisectorial strategic development project put forth by the Centre for Interdisciplinary Research in Rehabilitation of greater Montréal (CRIR) in Quebec, Canada and its members, in collaboration with a Montréal

☆ The study presented in this article — like the others in this special issue *Le centre commercial: un laboratoire vivant/Mall as Living Lab* — is part of the larger "CRIR-Living Lab Vivant" project described in the introduction to the issue: Desjardins M., Ville I., Mazurik K. (2014) On theoretical and methodological constructs of obstacles to social participation: The CRIR-Living Lab Vivant project. Alter, *European Journal of Disability Research*, 8 (3).

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http://dx.doi.org/10.1016/j.alter.2014.03.006

Keywords:
Rehabilitation
Participation
Inclusion
Physical disabilities
Living lab
Participatory action research

"renovation-ready" shopping mall, local community organizations, and local, national and international research and industrial partners. Beginning in 2011, within the context of the Mall as Living Lab (MALL), more than 45 projects were initiated to: (1) identify the environmental, physical and social obstacles and facilitators to participation; (2) develop technology and interventions to optimize physical and cognitive function participation and inclusion; (3) implement and evaluate the impact of technology and interventions in vivo. Two years later and working within a participatory action research (PAR) approach, and the overarching WHO framework of the International Classification of Functioning, Disability and Health (ICF), we discuss challenges and future endeavors. Challenges include creating and maintaining partnerships, ensuring a PAR approach to engage multiple stakeholders (e.g. people with disabilities, rehabilitation and design researchers, health professionals, community members and shopping mall stakeholders) and assessing the overall impact of the living lab. Future endeavors, including the linking between research results and recommendations for renovations to the mall, are also presented.

Mots clés :
Réadaptation
Participation sociale
Inclusion
Incapacités physiques
Laboratoire vivant
Recherche action participative

RÉSUMÉ

Nous présentons un projet stratégique multidisciplinaire et multisectoriel mené par le Centre de recherche interdisciplinaire en réadaptation (CRIR), en collaboration avec un centre commercial montréalais, des organismes communautaires et des partenaires de recherche et industriels locaux, nationaux et internationaux. Depuis 2011 ayant le Centre commercial comme laboratoire vivant, plus de 45 projets ont été amorcés pour : (1) identifier les obstacles et facilitateurs environnementaux, physiques et sociaux à la participation ; (2) développer des technologies et interventions pour optimiser la fonction physique et cognitive ; (3) implanter et évaluer l'impact des technologies et interventions in vivo. Deux ans plus tard, avec une approche recherche action participative (RAP) dans le cadre de la Classification International du Fonctionnement, du handicap et de la santé (CIF) de l'OMS, nous discutons des défis et entreprises futures. Les défis incluent la création et le maintien de partenariats, assurant une approche RAP pour engager plusieurs parties prenantes (ex. personnes avec incapacités, chercheurs, professionnels de la santé, membres de la communauté et parties prenantes du centre commercial) et évaluant l'impact global du projet. Les entreprises futures, qui incluent mettre en lien les résultats de recherche avec les recommandations pour les rénovations du centre commercial, sont aussi présentées.

1. Background

Research in rehabilitation has seen a resurgence over the past 10 years in Québec and Canada and is the main focus of activities within the Centre de recherche interdisciplinaire en réadaptation (CRIR). Unique in its structure extending over six rehabilitation institutions in greater Montréal, three partners and three universities, the CRIR is recognized for its strong clinical and interdisciplinary

research in the biomedical and psychosocial domains of rehabilitation, state of the art laboratories located within the rehabilitation facilities, and for its innovative, evidence-based and patient-centered approaches. Having the 'person with physical disabilities' as the focal point, research activities are organized within two research axes (Axis 1: Sensory, Motor and Cognitive Functions and Activities and Axis 2: Participation, Social Inclusion and Rehabilitation Services) and three priority development areas (Promotion of Health, Well-Being and Disability Prevention; Technology and Technical Aids and Knowledge Transfer & Exchange Activities).

In 2011, the centre received funding from the provincial funding agency *Fonds de Recherche en Santé* du Québec to conduct a four year strategic development project. This representd the culmination of concerted efforts from researchers, clinicians, administrators, local, national and international partners, and sensitized community organizations, whose goal was to foster change that would impact on participation and inclusion of people with physical disabilities across the life span.

Our project entitled A Rehabilitation Living Lab: Creating Enabling Physical and Social Environments to Optimize Social Inclusion and Participation of People with Physical Disabilities, stems from the converging goals of rehabilitation science and rehabilitation service providers that aim to enable individuals with a disability to resume, to the extent possible, their previous level of function and engage actively in meaningful life roles. It allows researchers to examine important issues beyond the walls of rehabilitation facilities to ensure people with a physical disability achieve optimal levels of participation/inclusion in their community. At the same time, it addresses concerns of rehabilitation professionals regarding the effectiveness of rehabilitation services in teaching practical community-living skills in a 'real' environment. When considering possible obstacles to successful re-entry into community life, following rehabilitation, one realizes there may be gaps in the provision of social and community-based services available for persons with disabilities who wish to resume daily activities.

Indeed, despite the existence of a number of social resources (e.g., adapted transport) and community-based groups, access can be plagued by a variety of problems due also to diminished financial resources (Cott, Wiles, & Devitt, 2007 and references thereof). In addition, the necessary adaptations within the physical and social environment that could facilitate participation and inclusion may not be in place. For example, numerous community settings remain difficult to access and use for many of these individuals. This can be due to either the physical characteristics of the environment, due to attitudes towards persons with disabilities or a lack of knowledge, or even a combination of these factors. Thus, we note that the design of buildings and public spaces tends to focus on the 'average' person that typically reflects the needs and the abilities of fit males in their early 30s. However, such a design focus may conflict with the reality of actual users, who tend to have different sizes and shapes and abilities. Universal Design (UD) posits that products and services should be usable by as many people as possible, regardless of disability, language barriers, or other obstacles (Kadir, Jamaludin, & Rahim, 2013); yet, although it has been embedded as a principle in accessibility regulations and building design codes used in North America, many public environments/settings fall short. There is no doubt that environments adopting principles of UD can promote equal status contact, allowing persons with and without disabilities to fully participate in common, shared environments, facilitating the interaction between all people (Lidwell, Holden, & Butler, 2003; Mace, 1997). Such interactions between persons with and without a disability are known to promote the appreciation of each other's "sameness" and thus work to reduce prejudice (Amsel & Fichten, 1988; Fichten, Shipper, & Cutler, 2005). However, UD does not directly address all of the social and human aspects of navigation and ease of movement in diverse settings, as it tends to focus mainly on aspects of the physical environment. Persons with disabilities may also face social obstacles that are behavioural and/or communicative in nature or related to perceptions and beliefs about a person's ability to function, thus influencing interactions and the way he or she is treated. As such, while a ramp may provide physical access to a shopping mall, it is no guarantee of access to an environment free of discrimination.

The policy provided in the document : À part entière : pour un véritable exercice du droit à l'égalité, Office des personnes handicapées du Québec (2009), addresses these issues and also provides the underpinning for our Rehabilitation Living Lab project. It aligns with the spirit and letter of the United Nations Convention on the Rights of Persons with Disabilities adopted in December 2006 (United Nations, 2006) and lays out the main challenges and priorities in terms of action for an inclusive Québec society including two priorities linked to the overall goal/vision of the rehabilitation living

lab: acting against prejudice and discrimination, and designing accessible environments. Our project's vision is also in accord with the policy's general objectives, which seek to reduce social isolation under the premise that it is not up to individuals to adapt to environments that have not been conceived to accommodate them, but rather it is up to society to develop itself while taking into account the diversity of its citizens.

2. The project

Our project has benefited from a partnership with the owners of a Montreal downtown shopping mall (Alexis Nihon) that offers CRIR researchers, clinicians and collaborators the opportunity to conduct concerted work in a naturalistic setting, within the environment of a shopping mall. This renovation-ready mall covers 400,000 sq. ft. of commercial rental space spread over three floors within a larger complex including office and residential spaces. It is situated next to a community college, a children's hospital and major transport access routes, including a Metro subway station. It is also at the crossroads of diverse socioeconomic strata, cultures and languages, thus possibly reflecting a microcosm of the local society around the shopping center where numerous encounters and complex transactions and activities (e.g. shopping, banking and socializing with friends) take place.

Since 2011, our research team of more than 50 researchers and their students, along with academic (McGill, Université de Montréal, Concordia, Université du Québec à Montréal, Université de Sherbrooke and University of Saskatchewan, University of Haifa, Unversity of Sienna) and clinical collaborators (Montreal rehabilitation facilities), as well as commercial/industrial (MOTEK Medical B.V. in the Netherlands, the Smith-Kettlewell Rehabilitation Engineering Research Center in San Francisco, the Adaptech Research Network in Montreal, INO Québec), and community partners (Altergo, the Student AccessAbility Centre Dawson College, the Cummings Jewish Centre for seniors, Mis-au-jeu, a theatrical group) have been working steadily in the shopping complex and the rehabilitation research labs in Montreal and internationally to create an inclusive environment that optimizes participation and inclusion for all. Three main objectives are pursued:

- identify the environmental, physical and social obstacles and facilitators to participation (shopping, meeting with friends, etc.) in the mall setting;
- develop technology (e.g., assistive devices) and interventions (e.g., rehabilitation treatments targetting participation in environments such as a shopping mall) to optimize physical and cognitive function, participation and inclusion of persons with disabilities;
- implement and evaluate the impact of technology and interventions in vivo (i.e., in the mall) on physical and cognitive function, participation and inclusion of persons with disabilities.

Research within the project is conducted in three main streams. The process is iterative: projects within each stream use a qualitative, quantitative or mixed-methods approach and allow observation, creation and actions revisited from multiple perspectives and in multiple iterations, corresponding to the emerging data and concepts developed. Stream 1 is exploratory and aims at obtaining a comprehensive understanding of the environment, the participants and the interrelationships among them as they interact within the social and physical context of the mall. In Stream 2, technological hardware and software, evaluation tools and kits are created and/or evaluated in scientific laboratories using techniques such as virtual environments. Stream 3 involves the implementation of different tools, kits and technological devices within the mall, and the assessment of their impact on participation and social inclusion.

We have adopted the Living Lab approach (Dubé, Sarrailh, & Kostecki, 2013). This involves: a public-private-consumer/citizen partnership, a *process* enabling persons to take active roles as contributors and co-creators in the research, development and innovation process, and the testing and development of products and services in a "real or naturalistic" environment corresponding to the environment in which real users/persons would use the innovation (Picard & Poilpot, 2011 and references thereof). The "persons" involved in our Living Lab include those living with a disability and rehabilitation service providers, since much of our research focuses on ways to improve clinical practice to better prepare persons with a disability cope with their daily challenges once discharged from rehabilitation.

Working also in the spirit of Participatory Action Research (PAR) (Baum, MacDougall, & Smith, 2006; Cargo & Mercer, 2008; Smith, Pyrch, & Lizard, 1993), researchers and different stakeholders, including people with disabilities, find themselves working together not only on individual projects, but also participating at higher administrative levels where decisions are taken about needed changes in the mall. As such, we believe the use of a Living Lab approach will better ensure the co-creation of innovation between researchers, users and private enterprise/industry.

Overall, 45 projects have been funded since the inception of the Living Lab program of which 11 have addressed the first objective of exploring obstacles and facilitators in the social and physical environment. Among those investigating the physical environment of the shopping complex, some have already provided recommendations on how to improve the acoustic and visual environment, as well as navigation around the mall, on foot or using a manual, motorized or smart wheelchair. Others have examined obstacles related to the social environment and have provided the groundwork for future intervention studies aiming to sensitize shopkeepers to the needs of persons with disabilities. Some key results from these research projects involving different stakeholders and persons with various disabilities are presented in the articles found in this special issue. Findings from these studies and others addressing the first objective have been essential in providing a comprehensive understanding of the changes needed to create an inclusive environment. Crucially, results from the different projects are being communicated to our partner COMINAR REIT, the real estate owner of the Alexis Nihon (AN) shopping center through monthly meetings, as well as the sharing of documents and results, to inform their decision-making regarding renovations currently underway. An important outcome of the partnership with the mall owners and the Living Lab approach is the inclusion of one of our executive committee members, Dr. Tiiu Poldma, in the weekly renovation planning meetings where she is able to interact during the meetings and provide the architects and management with evidence-based universal design recommendations. Thus, (i) AN is soon to install a ramp at the metro level entrance to improve wheelchair access to the shopping center for persons with disabilities studying/working at the college across the street (i.e., turning a 45 minute journey into a 10 minute one), (ii) colors and texture for the floor tiling have been chosen for better way-finding for people with visual disabilities, and (iii) a new branding and signage package is being considered to improve navigation and circulation. These are only some examples of upcoming changes in the mall.

With regard to the second and third objectives, our industry partners are facilitating the development of rehabilitation technologies/interventions, as well as the pilot testing of such interventions in laboratory and in vivo. For example, virtual reality environments and training programs, way-finding technologies, as well as an intelligent wheelchair have been developed and are currently being tested in the laboratories and the mall.

One of the key strengths of the project lies in its strong interdisciplinary and intersectoral nature, bringing together different research groups across disciplines (e.g., biomedical, clinical, psychosocial) and stakeholder groups (e.g., merchants, community-based associations, researhers) to conduct research in the mall. This strength is also a challenge arising from the multiplicity of disciplines and domains, clienteles, approaches and collaborators. To address this challenge, two parallel yet interconnected initiatives are underway to monitor progress, evaluate outcomes and identify research gaps. One of these initiatives by Dr. Francesco Grasso (University of Sienna) and his collaborators is using the International Classification of Functioning model to establish a common nomenclature for all projects. The second is spearheaded by Dr. Sara Ahmed (McGill University), who together with her team (Statistical and Evaluation Working Group), is using the Precede-Proceed logic mode[1] to create a comprehensive picture of the Living Lab research by linking completed or on-going projects to the overarching vision and objectives, thus allowing on-going tracking of progress and identification of research gaps. The development of a common evaluation framework within this complex, multisectoral research program is an important deliverable that promotes transferability of the implementation and evaluation process to other similar research environments and programs nationally and internationally.

[1] The Precede-Proceed Logic model is a graphic representation of a program showing the intended relationships between investments and results. This model is typically used for the evaluation of public health programs.

In April 2012, Drs. Dahlia Kairy (Université de Montréal) and Barbara Mazer (McGill University) created a community of practice (CoP) linked to the Living Lab project with the broad theme of 'Learning together to improve rehabilitation, participation and inclusion for people living with disabilities'. The CoP's mandate is to: (1) allow for the sharing of stakeholder experiences/perspectives on issues related to creating enabling and inclusive environments, which will in turn inform research taking place in the mall; (2) invite stakeholders and partners to participate in the shaping of project objectives/goals, data collection, interpretation and dissemination of research findings; and (3) set research priorities for future projects in the mall. The CoP will be instrumental in evaluating the outcomes/impact of the project on the different stakeholders, in terms of their use of research findings or knowledge in their individual practices, as well as evaluating changes in perceptions or attitudes of CoP members with regard to issues pertaining to equity and disability, capacity building and the emergence of new community initiatives. Furthermore, the CoP will strengthen the implementation of the participatiory action research approach within the mall. Participatory action research projects have been shown (Cargo & Mercer, 2008) to: (i) to enrich the interpretation of research findings through the integration of various stakeholder perspectives, (ii) increase the potential for wider dissemination and translation of research results, (iii) promote capacity building, empowerment, and ownership of nonacademic partners, (iv) improve existing programs or create new programs, practices, services, and policies, and (v) produce research products or deliverables tailored to the needs of the implementers and end-users (i.e., users of the mall). This last outcome could include virtual reality software for clinical use with persons with stroke or the adaptation of intelligent power wheelchairs to move around the interior environment of the mall.

3. Living Lab Initiatives & Future Directions

Inherent in the Living Lab approach and Participatory Action Research is the continuous transfer and exchange of knowledge (KTE). The current issue of the *ALTER* journal, containing six articles stemming from research either conducted within the Living Lab or inspired by it, is one such manifestation. Furthermore, in addition to implementing the CoP as an important KTE tool for the project, we have also organized meetings and networking events, developed KTE platforms, e.g., the website with a public component and an intranet: www.crir-livinglabvivant.com and e-newsletters.

In the next two years, we will continue to triangulate knowledge gleaned from past findings and current research projects, as well as from recommendations from the CoP and from the two initiatives developing a common evaluation framework. Thus, based on a clear understanding of obstacles and facilitators to participation and inclusion in the mall, we are now conducting research aiming to develop tools, while technology-based and clinical interventions are currently being tested in labs or in vivo. For example, the newly developed intelligent power wheelchair and its adapted GPS system are being tested inside the living lab, while modules evaluating cognitive and locomotor strategies when navigating and shopping in environments such as a shopping mall are being tested in the lab environment. We then proceed with the evaluation of adaptations and changes to the physical and social environment from the perspectives of the different users, especially those of individuals with disabilities. Since the beginning of this project a number of other changes have also been taking place as the Living Lab project creates a ripple effect across different sectors. Specifically, rehabilitation professionals are re-examining their treatment approaches so as to better respond to the 'real-life' needs of their patients; thus, following the results of focus groups among individuals with stroke and communication difficulties and their caretakers, speech language pathologists are discussing new treatment approaches to better prepare persons with communication difficulties to participate more confidently and ably in environments such as a shopping mall. Other environments, such as museums (e.g., Musée de civilisation du Québec) are questioning their degree of accessibility and inclusion; students from diverse university departments (e.g., medicine & social sciences) with their mentors, are learning together in the ecologically-valid environment of the mall; furthermore, the general public is increasingly being sensitized to issues of 'disability' and 'rehabilitation' through e-newletters from the project's website and lay publications such as the journal published by the shopping mall owner and circulated among merchant tenants of the mall, through general public presentations and through sensitization initiatives and projects aiming to raise awareness on disability.

With the current project, CRIR has been given the opportunity to experiment with the Living Lab approach and we feel we have been successful in moving forward. However, since we have only just begun our third year of research, it is still difficult to measure the "performance" of the Rehabilitation Living Lab, since the global performance of a Living Lab is directly linked to its level of maturity (Dubé et al., 2013). Nevertheless, it is already growing and producing results and deliverables that are not only impacting the environment of the mall, but are also radiating to other settings. To conclude, we are confident that, given CRIR's foundation, built on excellence in rehabilitation research and the strong partnerships with diverse stakeholders who are deeply committed to creating enabling environments for persons with physical disabilities, we will see an increase in scope and number of Living Lab projects that will foster a more inclusive society for all.

Disclosure of interest

The authors declare that they have no conflicts of interest concerning this article.

Acknowledgement

The project reported here is a Strategic Initiative Project and is supported by funding from the Fonds de Recherche en Santé du Québec. This project is also supported by the CRIR and the rehabilitation facilities, members of CRIR.

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