

## Research Articles

### **To Include or Not to Include? Realities, Challenges and Resistances to the Participation of People with Disabilities in Seniors' Organizations**

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**Abstract:** People with disabilities are often excluded from mainstream seniors' organizations. A participatory action research project was undertaken in a seniors' leisure association to better include members with disabilities. Results underline the importance of understanding the interaction of individual and environmental factors when looking to support the participation of seniors with disabilities.

**Keywords:** Social participation; Inclusion; Senior

### **Introduction**

Contemporary discourses on demographic aging emphasize the value of older people's social participation as a way to maintain both optimal health (World Health Organization, 2002, 2007) and social roles (United Nations, 2002, 2008). In most countries with an aging population, numerous formal seniors' organizations offer a wide variety of participation opportunities such as volunteering, social and recreational activities. However, although many older people may choose to go to such participatory spaces and find meaningful and satisfactory forms of involvement there (Gilmour, 2012; Zedlewski & Butrica, 2007), those settings may be less accessible to people with disabilities (Lacroix & Raymond, 2015). Various factors could make it difficult for them to join such organizations--architectural and physical issues or ableism-linked attitudes.

Since the absolute number of older people with disabilities will increase as the population ages (Institut de la statistique du Québec, 2013; World Health Organization, 2014), it is urgent to consider how to improve the access of older people with disabilities to, or prevent their exclusion from, mainstream seniors' participatory settings. Though such efforts have been and continue to be made in educational and work environments (United Nations, 2006, 2014), they are much less noticeable in older people's clubs, associations and movements (Bigby & Balandin, 2005; National Council on Ageing and Older People & National Disability Authority, 2006; Russell, 2009). This situation echoes the paucity of evidence addressing this issue in the scientific literature or public policy regarding the realities of aging with disabilities (Jeppsson Grassman & Whitaker, 2013). Reasons for this lack of visibility include, until recently, the relatively limited longevity of people with disabilities (Sheets, 2010; Verbrugge & Yang, 2002) as well as the

desire of disability researchers and activists not to conflate disability with the concepts of decline or illness commonly associated with aging (Jönson & Taghizadeh Larsson, 2009).

Therefore, when the board members of a seniors' leisure association, the *Compagnie des jeunes retraités du Plateau de Charlesbourg* ("Young Retirees Group," hereafter CJR) asked for our support in developing an internal policy aimed at including people with disabilities in their activities, it seemed like an exceptional opportunity to study the issue empirically, following a three-year participatory research project with older people with disabilities concerning their experiences of social participation (Raymond & Grenier, 2015; Raymond, Grenier, & Hanley, 2014). We assumed that the proposal made to us was the chance to turn the situation upside down and better understand how older people "without disabilities" consider the presence and participation of older people "with disabilities" in "their" organizations. A participatory action research (PAR) project was undertaken around the implementation of CJR's inclusion policy that combined data collection regarding members' needs and visions, raising awareness of various aspects of aging, impairments and activity limitations, and trying different solutions on the individual and collective level. This article presents the results of the first wave of data collection, which explored CJR members' thoughts and experiences with regard to including members with disabilities. The aim was to better understand some of the realities, challenges and resistance related to the implementation of an inclusion policy in the association.

This article begins by highlighting trends in the literature concerning the participation of older people with disabilities in mainstream community settings and the emphasis on personal factors rather than organizational conditions. It then introduces the chosen theoretical model, the Human Development Model - Disability Creation Process, version 2 (HDM-DCP2), which links personal and environmental factors of social participation. This led us to more acute insights about how discourses and practices with respect to inclusion are framed in CJR. Next, the details of the participatory method used in the CJR project is outlined and results are provided concerning how micro, meso and macro factors mediated the possibilities for people with disabilities to be included in the association, shifting the focus from individual factors to more collective ones. Discussions focused on the challenges and tensions that emerged from considering the inclusion of people with disabilities as a social problem needing to be cooperatively addressed rather than as individual accommodations needing to be made each time, or as problematic demands disrupting the normal course of events occurred. It is essential to understand this change of perspective if we want to achieve inclusion for all.

### **Literature Review: A Missing Intersection**

Participation and inclusion have been core themes of international social movements and research in the field of disability for the last four decades (Barnes & Mercer, 2013; Fougeyrollas & Gaucher, 2013; United Nations, 2014). However, the implementation of such ideas has tended

to focus on issues that affect children and working age adults such as education, parenting and employment (Ingvaldsen & Balandin, 2011; Priestley, 2003). Even when it does address the social participation of older people with disabilities, most of the literature focuses on work-like activities such as volunteering (Balandin, Llewellyn, Dew, Ballin, & Schneider, 2006; Narushima, 2005; Tang, 2009). Inclusion in cultural, political or leisure activities has received little attention.

This lack of attention is surprising, considering that studies have linked social participation and health (Baker & al., 2005). Although the benefits of social participation on health are well-known, identifying direct correlation is more difficult (Wahrendorf & al., 2006). However, participation is associated with a more efficient promotion of health and prevention of diseases (Bath & Deeg, 2005; Zuzunegui, 2003), an enhanced adjustment to transition through role substitution (Choi & al., 2007; Van Willigen, 2000), and more frequent and satisfying social contacts (Litwin & Shiovitz-Ezra, 2006; Wahrendorf & al., 2006). Moreover, participation in organized sports, sociocultural or other leisure activities are known to create both a pretext to go out and a shared space where people can meet their individual needs while helping others (Raymond, Sévigny & al. 2015). Seniors who participate in this kind of setting show better health (Cohen & al., 2006), involvement in more activities (Cohen & al., 2006; O'Shea & al., 2012), and more social contacts (O'Shea & al., 2012; Wang & Glicksman, 2013).

However, few studies have focused on the societal participation of older people with disabilities in mainstream community settings (Lacroix & Raymond, 2015). At present, it seems that older people with disabilities are more likely to be included in specialized settings--with organizations that have trained staff and can offer adapted services (Savard, Leduc, Lebel, Beland, & Bergman, 2009; Strain, 2001). However, one study showed that even if going to such centres has a positive outcome, they do not cater to the needs of people who have been included in "normal settings" their whole life (Gaugler & Zarit, 2001). Even though people with disabilities may face numerous obstacles when trying to participate in mainstream associations (Raymond, 2014; Raymond, Grenier, & Hanley, 2014), with appropriate accommodations and assistance they could participate actively in community life (Bickenbach et al., 2012).

The potential to participate in chosen, significant, and self-realizing activities requires contextual and individual conditions for access to be met (Jeppsson Grassman, 2013). Most studies examining the participation of older people with disabilities focused on individual factors, such as cognitive, sensory, and physical limitations (Anaby et al., 2009; Paillard-Borg, Wang, Winblad, & Fratiglioni, 2009). Their impacts on participation are well-documented and guide appropriate interventions by rehabilitation specialists on a personal level. However, this approach puts the responsibility for inclusion solely on the shoulders of the person with

disabilities (Balandin, Llewellyn, Dew, & Ballin, 2006; McConkey & Collins, 2010; Percival & Hanson, 2005).

In other words, the literature is inconclusive about how best to support the involvement of older people with disabilities at the community level. However, certain trends point to realities that can limit the participation of older people with disabilities in mainstream organizations, especially in the adaptation of activities and reactions of other participants. For the organization itself, adapting activities to the needs of people with disabilities can be challenging (Tang, Morrow-Howell, & Choi, 2010). For the staff, accommodations are seen as affecting the experience and satisfaction of other participants, thereby limiting service delivery for all (Balandin et al., 2006; Ingvaldsen & Balandin, 2011). This viewpoint shows a lack of knowledge among people working in seniors' organizations (Balandin, Llewellyn, Dew, & Ballin, 2006; McConkey & Collins, 2010). Even though staff understand the importance of including all older people, researchers concluded that it might be difficult to achieve this goal without more specialized workers trained to provide individual assistance to people with disabilities (Balandin, Llewellyn, Dew, & Ballin, 2006; Bigby & Balandin, 2005; Ingvaldsen & Balandin, 2011). In addition, physical obstacles often prevent access to the locations where mainstream organizations conduct their activities (Bigby & Balandin, 2005).

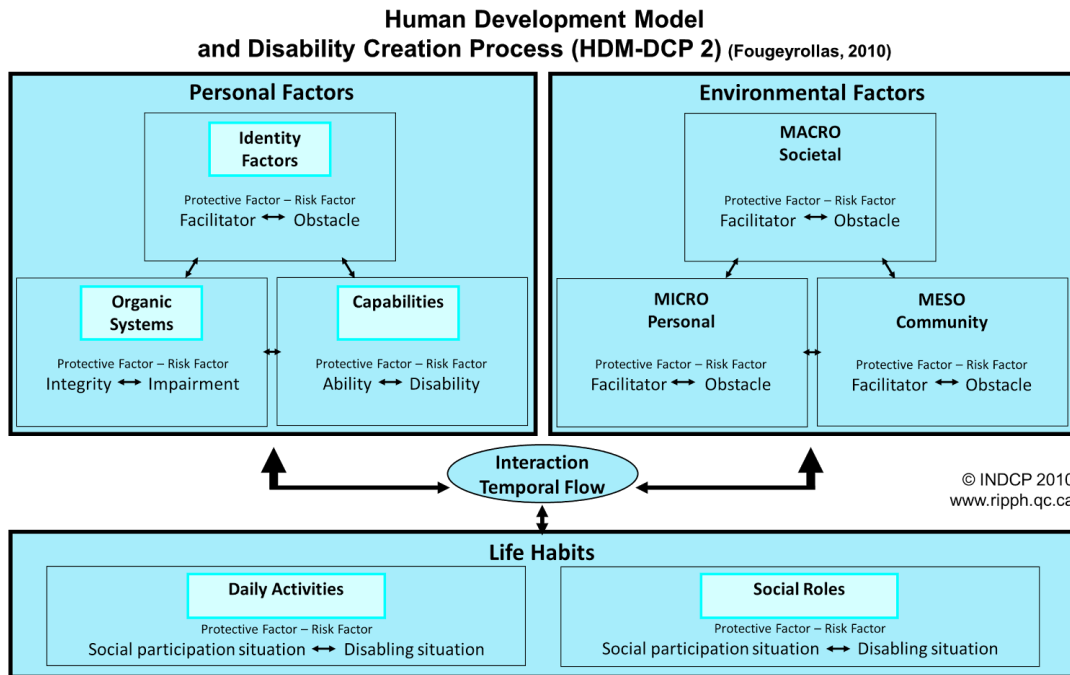
In short, some studies have started to explore problematic issues at the interface between aging and disability, with one such issue being equal access to social activities. However, results are scarce, are often related to a specific reality such as intellectual disability, and do not provide an evaluation of actions that can make changes at the environmental level, ensuring inclusion for all. This study fills this gap by documenting the vision of inclusion articulated by members of CJR.

### **Human Development Model - Disability Creation Process**

The Human Development Model - Disability Creation Process (HDM-DCP2) shown in Figure 1 is a theoretical model that considers disability as a relative reality, constructed through the connection of biological, functional, physical and cultural elements. There are no disabled people per se, but rather people unable to perform their daily activities and social roles because of an inadequate interaction between personal and environmental factors (Fougeyrollas, 2010). Such inadequacies put individuals in a disabling position while an adequate interaction would allow them to achieve social participation. Both personal and environmental factors can act as facilitators or obstacles to social participation. Personal factors include the individual's identity, organic systems and capabilities. Environmental factors refer to dimensions defining the way a society is organized. The model posits three categories of environmental factors: personal (micro), community (meso) and societal (macro) (Fougeyrollas, 2010). The personal environment consists of things in the person's immediate environment, such as family and

friends. The community environment comprises organizations and services used by the person outside the home. Finally, the societal environment contains rules, regulations and programs that can affect the individual’s participation.

**Figure 1: Human Development Model - Disability Creation Process (HDM-DCP2)**



Reference : FOUGEYROLLAS, Patrick (2010). *La funambule, le fil et la toile. Transformations réciproques du sens du handicap*. Québec : Les Presses de l’Université Laval, 315 p.

Summary of Figure 1 entitled Human Development Model – Disability Creation Process (HDM-DCP2). This image is composed of two squares and one rectangle. The top left square illustrates personal factors. Inside this square, three components of personal factors are detailed: first, identity factors, which can be placed on a continuum, symbolized by a bidirectional arrow, between facilitator and obstacle; second, organic systems, between integrity and impairment; and third, capabilities, between ability and disability. The top right square illustrates environmental factors. Inside this square, three components of environmental factors are detailed: macro societal, micro personal and meso community factors. These three factors can be placed on a continuum, symbolized by a bidirectional arrow, between facilitator and obstacle. Below those squares is a rectangle illustrating all of the life habits: daily activities on the left and social roles on the right. Both are placed on a continuum, symbolized by a bidirectional arrow, between social participation situations and disabling situations. Between these shapes is an oval conveying the reciprocal relationships and temporal flow between all components by means of bidirectional arrows. The possibility for a person to realize her life habits his linked to the interaction and flow between personal and environmental factors.

The HDM-DCP2 model helps to understand and potentially modify disabling settings and dynamics. Since it conveys the whole experience of disability, like other relational models (Shakespeare, 2014), it does not focus primarily on medical or structural factors. In our case, the HDM-DCP2 model enabled us to tackle complexity when analyzing how discourses and practices with respect to the inclusion of members with impairments are framed in CJR. For instance, the emphasis on individual biological or attitudinal factors to explain the social participation of older people with disabilities, so dominant in both scientific and population discourses, could be revisited and connected to collective, contextual factors, but without overlooking the importance of personal realities.

### Participatory Methods

The results presented here are derived from a participatory action research project rooted in CJR, a seniors' leisure association offering its 1800 members more than 100 activities each year. As a non-profit organization, it is managed by a group of 120 volunteers, board members and activity managers. It offers a wide variety of activities, such as sports (tennis, walking group, snowshoeing, cycling, cross-country skiing, golf, etc.), social (meetings, conferences, dance classes, etc.), cultural (museum visits, signing group, language classes, music shows, etc.), travel, etc. The association was created in the mid-1990s, a period marked by the objective of attaining "zero deficits", or provincial budget balance. Numerous public employees obtained an early retirement, hence the name "Young retirees" in CJR's name. So in 1994, a group of recently retired individuals from a White and middle-class neighbourhood decided to create a social club allowing for more "active" or "dynamic" leisure compared to typical golden-age activities.

When celebrating CJR's 20<sup>th</sup> anniversary in 2014, the board members realized that their aging membership (50% of members were 70 and older) was starting to face limitations in their participation. To avoid having anyone leave the organization because of disabilities, in 2013 they adopted an internal policy on inclusion. This document laid the groundwork for the definition of key concepts, such as inclusion, disabilities, and social participation. It also promotes the values important for the association. However, the application of the policy was not operationalized. A Participatory Action Research (PAR) project was set up to ensure proper implementation and evaluation of this policy. A three-year research grant for the project was obtained from the government of Québec, one of ten provincial administrations in Canada.

While PAR encompasses a wide variety of research practices, it is fundamentally about involving people in the production of knowledge regarding problems that concern them, and in the framing and application of solutions that are in line with their experience (Chevalier & Buckles, 2008; Reason & Bradbury, 2008). It appeared to be a meaningful approach for CJR members, who were eager to be at the forefront of the project. Undertaking PAR involves trying to change the relationships between researchers and participants in both the process and the

outcomes of the research; the sharing of expertise, power and responsibility is experienced as a tool to build mutual benefits, create relevant data and achieve social change (Bradbury & Reason, 2003; Fals Borda, 2001; Pain, Kindon, & Kesby, 2007; Reason & Bradbury, 2001). From the outset of the PAR project, we created a “research group” composed of seven CJR members, a social worker, an academic (1<sup>st</sup> author) and a research assistant (2<sup>nd</sup> author). Members participated in all research steps and tasks: developing the research protocol, designing the data collection tools, leading or co-leading the interviews, analyzing and interpreting the data. The researcher and research assistant provided training for the committee members to ensure that all participants were informed and comfortable.

The first phase of the project consisted of collecting data about what CJR members thought and experienced with regard to the inclusion of members with disabilities. Our aim was to better understand the circumstances, dilemmas, possibilities and conflicts related to the implementation of an inclusion policy in the association. Two methods were used. First, individual interviews were conducted with members who manage the association’s activities. Second, seven focus groups were conducted with members. In all, 60 participants were invited to share their perceptions in response to questions. We saw these individual and group interviews not only as a way to gather useful data for the implementation of the policy but also to sow the seeds of change within CJR, making people aware of the research project and its goals. The questions guiding the interviews could be summarized as follows: in CJR, could members who develop impairments remain involved in chosen activities? Could prospective new members with different types of disabilities be admitted and included? Following the dissemination and acceptance of the results in CJR, we planned to develop solutions to the problems identified.

All interviews and focus groups were recorded and transcribed, and N’Vivo was used to categorize text segments from the transcripts into open categories at first (individual factors, environmental factors, solutions, exclusion situation), followed by more selective coding designed to make principal obstacles emerge (Creswell, 2013). Validity of the results was supported by three strategies, some of which involved the participants themselves (Padgett, 2008): prolonged engagement in the field for the research team involved; member checking by participants of the project in all steps; and peer debriefing and support. Reliability was ensured by using intercoder agreement in all the coding steps, including development of the codebook and the actual coding (Creswell, 2013). Each source was coded independently by a member of the research team and a CJR member. Agreement reached 70%, which was considered acceptable since it was the first experience with research for many of the members.

**Results**

The results presented here show the perspective of CJR members reflecting on the rationale of including fellow members who already have or develop disabilities, and the inherent challenges and difficulties involved in doing so. They offer unique insights concerning a central question in aging societies: Would an increasing number of older people with disabilities be able to join mainstream participatory spaces, including seniors’ organizations? It is essential to answer this question if we are to achieve equity in both aging policies and trajectories.

In total, we collected information from seven focus groups (46 participants) and twelve individual interviews (14 participants; three asked to do the interview together since they managed the same activity). Composition of the sample is shown in Table 1.

**Table 1: Distribution of sample by source, age and sex (W=Women, M=men)**

Source	Age/Sex	Source	Age/Sex	Source	Mean age/Sex
Interview 1	76/M	Interview 7-8-9	70/1W-2M	Group 1	70/6W
Interview 2	67/M	Interview 10	66/M	Group 2	75/2W-2M
Interview 3	*/W	Interview 11	70/W	Group 3	71/7W-1M
Interview 4	72/M	Interview 12	66/M	Group 4	75/3W-3M
Interview 5	67/M	Interview 13	71/W	Group 5	74/5W-7M
Interview 6	76/M	Interview 14	70/W	Group 6	70/5W-1M
				Group 7	70/2W-2M

\* Participant refused to give her age

Factors influencing social participation can be categorized, as suggested by the HDM-DCP2, into individual and environmental dimensions. Since our aim is to gain a better understanding of how CJR members feel about the implementation of an inclusion policy in their organization, results focus on environmental factors that are seen to support or hamper inclusion, i.e., micro (how “regular” CJR members talk and act about disabilities), meso (how activities are planned and carried out in CJR) and macro (the discourses and management structuring CJR) environmental factors. The results section ends by addressing how individual factors in the group targeted by the inclusion policy, i.e., members with disabilities, are framed in the participants’ accounts.

**Micro Environment: Them vs. Us**

This first category of environmental factors led us to consider how CJR members’ ideas and interactions concerning inclusion might impact the inclusion policy. From the start, it must be said that the way disability was conceived by the study participants was profoundly anchored in



the metaphor of fatality, which also ties in with the way aging is constructed. Following that logic, participation seems unattainable after a certain age. Here, being too old appears to be a convincing reason to abandon an activity:

“At one point, you have to limit your activities, it’s unreasonable [to continue], you’ve reached that point, you are 72 years old.” (Interview 12)

While aging is mentioned as a negative discourse, as something people don’t want to think about, a loss of capacities is seen as its worst outcome:

“[People will say]: my good days are gone. [...] We can’t escape it [aging]. It’s an eye-opener, people are scared.” (Group 5)

“I think that when you get older, you have to grieve for all of your abilities that decline progressively.” (Interview 5)

Even though aging and disability are linked in people’s minds, the latter being the unavoidable result of the former, the study participants distinguished between “active”, “normal” older people, who made up the majority of CJR members, and older people with disabilities. When speaking about the participation challenges faced by people with disabilities, it was mostly a matter of “them,” not “us”:

“These people [with disabilities] are always exceptional cases. (...) As a rule, you organize your activity for normal situations.” (Interview 1)

Since acquiring or developing disabilities is constructed as a predictable but (hopefully postponed) dark side of aging, when it happens it might entail a mix of giving up and coping. For instance, members in this situation should accept their situation, be nice, reframe the nature of their involvement and ask for help when necessary:

“I noticed that high achievers especially, when they experience difficulties, find it hard to accept a change of group [level], even if it would be more enjoyable. It’s a difficult situation to accept.” (Interview 5)

“That’s how it is. You have to accept that you have a problem: it is not CJR’s problem. Adapt, make changes if you can; if you can’t do it [the activity] anymore, just stop and do something else.” (Group 4)

However, when the individuals concerned were well-integrated in the CJR before the onset of disabilities, when they were supported by a group of close relatives, the impact of impairment seemed to be attenuated:\

“So he came, his wife picks up the balls for him and gives them to him directly in his hand so he can shoot. The other members were OK with this, we’ve known him for several years, and everything was fine. He was a lot slower than he used to be, but everyone accepted him. He kept his cheerful attitude and all was good.” (Interview 3)

“Speaking of him [man with a disability], we found a way to give him the impression of still being part of the activity, he drives the back-up car [during a biking expedition]. We always need one or two of those. He is happy; he follows his group of friends with whom he spent time for years, while still being useful if someone has a problem or an accident.” (Interview 4)

Thus, in some ways, micro discourses about the CJR inclusion policy restricted the goal of being more welcoming to people with disabilities to a specific aspect that makes it the exception, not the norm:

### **Meso Environment: Accommodation Up to a Certain Point**

In the context of a leisure association offering hundreds of activities for older people, implementation of an inclusion policy is likely to be profoundly mediated by the way things are managed at the organizational and interactional levels.

Volunteers are responsible for planning and running activities and this seems to be a huge responsibility:

“It [planning the activity] will become burdensome, I agreed to get involved but it can be... I don’t want to have more work than when I was working.” (Interview 5)

Including people with disabilities in their activities poses an additional challenge for organizers. Some leaders lack knowledge of the realities and needs of people living with disabilities. Some are not interested in learning the skills necessary to cope with these situations:

“Unfortunately, I do not think that all of the organizers are available or want to spend time and energy preparing to deal with such situations.” (Interview 4)

Including people with disabilities frequently requires some accommodation with respect to architecture, equipment or rhythm. Ineffective accommodation practices can lead to the marginalization or exclusion of the individuals concerned:

“We had to put the balls directly in her hand, almost shoot them for her, pick them up after, she was slowing the whole group. The day after, I called her and told her: “Look, don’t you think that a certain level of flexibility and ease is necessary to play this sport?” [...] She said: “I’d better stop going.” I replied: “I won’t put words in your mouth but that is what I was expecting you to say.” [...] Obviously she never came back. I’ve never seen her again.” (Interview 3)

“I see another problem in that. Twice I’ve seen people stop an activity that they could have continued because of, for example, a foot or knee operation. This situation happened in one group, the person stayed home, she couldn’t come because she couldn’t drive, so she stopped the activity.” (Group 3)

Beyond organizational accommodations, the participants’ accounts showed more relational, interactional meso issues. For example, participants expressed a desire for belonging and continuity in the composition of groups. Newcomers or people with disabilities are seen as not being one of the “gang,” and thus as jeopardizing the cohesion of the association:

“There are the younger members, barely 60 years old, newcomers to CJR, dynamic and wanting to perform, facing others, 80 years old, slowing the pace of the activity. These people are not always ready to accept constraints; they are here to have fun for themselves.” (Interview 4)

When the group decides that someone does not fit in or have his/her place, it is assumed that it is that person’s responsibility to realize it and change activities. These situations cause exclusion:

“People will say: she knows she can’t do it anymore, she just has to stop coming. This idea will be spread around a lot.” (Interview 11)

People in our sample explained this kind of behaviour as being mainly due to a lack of knowledge about disability and a fear of change. It is easier to ignore a problem than address it:

“But I see... there are people who won’t accept it. There are some people who can’t accept my decreased abilities because I’m not the same person anymore. I won’t lie to myself.” (Interview 11)

“People don’t know what to do. They stand there gaping, they know about the situation but they also know that if they don’t talk about it, it may be nipped in the bud, go away... they don’t know what to do.” (Group 3)

All told, the policy for inclusion was perceived as being superimposed on other policies, emerging from customary ways of doing things and networking.

### **Macro Environment: Shifting Purpose**

Demographic aging and related public policy changes could impact on how disability is handled in a seniors' organization. There is a growing absolute number of older people, which may partly explain why CJR is facing rapid expansion in its membership, from 500 to 1800 in less than a decade. In becoming such a large organization, the study participants wondered if meeting individual needs was realistic:

“Isn't that the problem? When an organization becomes too large, too big, it can't cater to the individual needs of its members.” (Group 1)

Secondly, because CJR is managed solely by volunteers, expectations regarding the involvement of organizers in achieving inclusion are seen as necessarily limited:

“As you say, organizers have to be equipped, trained because they don't know what to do. [...] You see, they are all volunteers and might not know everything. They put together a group, everybody has fun but they don't always know that there are conflicts in the group.” (Group 3)

“If I put myself in the organizers' shoes, they have a lot of goodwill but they are all volunteers. They might want to organize an activity but maybe they don't have the right attitude, aren't diplomatic enough to know how to tell them [people with disabilities] that [they can't be in the group anymore].” (Group 7)

Aging of the membership and the ongoing larger proportion of people with disabilities within it raises issues about what the association's purpose should be. There appears to be a disconnect between sticking to self-governing and stimulating recreational activities and the possibility of adapting or changing CJR to accommodate what are viewed as minority situations:

“It is not the CJR's responsibility to guide the person toward something else [other activities]. I don't really know what the CJR could do in such situations [when people with disabilities ask for support].” (Interview 7-8-9)

“It means that we will accommodate them as long as it doesn't disturb the other participants. Accommodations are individual; if we have to get a little bench for him, we'll do it, but nothing more. We can't play for him after all!” (Interview 3)

At the macro level, the policy of inclusion is partly perceived as being overly demanding for CJR, which was founded as a social club for “young” retired people. Again, seeking to integrate disability as something usual that must be taken into account, was felt by the participants to be incompatible with dominant and dichotomizing discourses about the two successive trajectories within aging: before and after the onset of a loss of capabilities.

### **Connecting Environment to Individual Factors: Potential Ignored**

This study did not specifically investigate how CJR members with disabilities envision their own participation and inclusion in the organization. At this stage, we were interested in seeing how “average” members describe individual issues and realities of members with disabilities. Although several participants disclosed disabilities during the interviews and focus groups, they generally considered their own situation to be different from that of people with “more” or “worse” disabilities.

When invited to describe the characteristics of fellow members with disabilities, the participants overwhelmingly pointed to poor health; in all the interviews and focus groups, it was mentioned as a negative input for inclusion. Whether permanent (loss of mobility, hearing, vision, cognitive problems, depression and anxiety, pain, allergies) or temporary (caused by accident, surgery or disease), health issues are always linked to a decrease in participation. Cognitive limitations especially are seen as making inclusion in a group setting intolerable. Moreover, the large majority of participants mentioned the decline in capacities as restricting participation. While physical limitations (vision, hearing, mobility, and loss of endurance, strength and velocity) are seen as important, two situations can be singled out as particularly incapacitating: loss of the ability to drive and dependence on others to accomplish daily tasks. In sum, people with disabilities are viewed in a negative light that only considers their deficits and ignores their potential or strengths. The linking with environmental factors shows consistency in the dynamics and decisions that have produces exclusion.

### **Discussion**

Our results confirm the importance of exploring the interaction of individual and environmental factors when seeking to better support the membership and participation of people with disabilities in a seniors’ leisure association. In fact, while the scientific literature still focuses on individual factors when addressing specific needs and difficulties of seniors with disabilities (Lacroix & Raymond, 2015), this study shows that environmental factors are crucial if we do not want disabilities to be the dividing line between older people who can and cannot participate in mainstream community settings.

When analyzing and merging micro, meso and macro environmental factors regarding the inclusion of people with disabilities in CJR, two transversal trends emerged: first, disabilities are

seen an exception; second, when members are keen to make some type of accommodation to facilitate the participation of people with disabilities, the regular course of activities must not be affected. Connected with individual factors, these interpretations point to the participation of members with disabilities in seniors' organizations as unusual, disconcerting and possibly disruptive. Such tension between personal situations and environmental conditions poses a serious threat to the participatory ideal framing contemporary discourses and policies in both the aging (United Nations, 2008) and disability fields (United Nations, 2014).

Regarding disabilities as being shaped as a somehow singular experience, this result could appear striking since it is known that both the proportion and the absolute number of older people with disabilities are increasing (Murray et al., 2014). For instance, 26% of people aged 65 and over in Québec present moderate or severe disabilities, and this proportion rises to 57% for all kinds of disabilities (Institut de la statistique du Québec, 2013). But if the intersection of old age and disabilities is far from being the exception, why is it seen this way? Why did our study participants make such a clear distinction between “us” (members without disabilities) and “them” (people with disabilities)?

Many years ago, authors started to address stereotypes associated with older people with disabilities and the fact that older people “without disabilities” do not like to mix with the former, partly because seeing them could evoke the inevitability of future decline, the genuine embodiment of failure (Cohen, 1988; Katz, 1996; Lund & Engelsrud, 2008; Minkler & Fadem, 2002; Pardasani, 2010; Raymond, Grenier, & Hanley, 2014b; Zarb, 1993; Zarb & Oliver, 1993). This dichotomization echoes another dichotomy evident in policy and media discourses, where older people are either healthy and willing to participate in society, or not healthy and expected to stay at home or in specialized settings (Biggs, 2004; Jeppsson Grassman & Whitaker, 2013; Lagacé, Laplante, & Davignon, 2011; Raymond & Grenier, 2013; Rozanova, 2010). Aging successfully is about not looking old, sick or limited (Paillard-Borg et al., 2009; Priestley & Rabiee, 2002).

In CJR's day-to-day operations, the perception of disability-related realities as something occasional and discontinuous leads to case-by-case management that has the potential for inequity. One problem is anchored in the Victorian rhetoric of deserving and undeserving poor (Katz, 1989), which was also used to critically review disability policy (Roulstone & Prideaux, 2012), i.e., some members with disabilities deserve consideration and accommodation while others do not. If the former are nice, easy-going people, well-known within CJR, eager to admit their limitations and not be too demanding, and willing to accept unsatisfactory but continuing membership, inclusion is likely to be more straightforward and effective. While perceptible at the micro level in the participants' accounts about fellow members with disabilities, this pervasive posture permeates meso and macro level conditions for participation. In other words,

members with disabilities must undertake by themselves the journey of adjusting their involvement in CJR, taking environmental circumstances and factors into account.

Coming back to the second transversal trend in the results, while no one is opposed to virtue and the idea of inclusion looks like an attractive, conceivable solution allowing members with disabilities to participate in CJR, it must not affect the experiences of “regular members” in the association. Indeed, changes likely to improve inclusion are perceived as complicated and annoying. Since it seems unproductive to attribute this (mis)understanding to egotism or apathy, the existing literature could help to understand this reluctance to make changes.

For example, research has documented the difficulty mainstream organizations have when tailoring their activities to the situations and aspirations of people with disabilities, especially group activities (Savard et al., 2009; Tang et al., 2010). In some cases, specific accommodations are seen as affecting services and collective experiences for people without disabilities, leading organizations to question the way they achieve their mission (Balandin, Llewellyn, Dew, Ballin, & Schneider, 2006; Ingvaldsen & Balandin, 2011). Researchers also found a lack of knowledge regarding the realities of people with disabilities, insufficient resources to provide support when needed, and the inadequacy and inaccessibility of physical settings (Balandin, Llewellyn, Dew, & Ballin, 2006; Bigby & Balandin, 2005; McConkey & Collins, 2010).

It is remarkable to note that these meso obstacles could be preceded or amplified by micro prejudices against older people with disabilities rooted in “local” internal relationships and interactions, or macrosocial narratives about aging and disability (Ingvaldsen & Balandin, 2011; Lund & Engelsrud, 2008; McConkey & Collins, 2010; Paillard-Borg et al., 2009; Priestley & Rabiee, 2002). Moreover, this environmental analysis shows substantial consistency in how people with disabilities are presented in the data. The relational framework proposed by the HDM-DCP2 model helped to identify and explore complexity, showing that the question of inclusion is challenging at all levels.

### **Final Thoughts: How to Produce Change?**

If we accept that older people with disabilities are able (Jeppsson Grassman, 2013) and have the right (United Nations, 2006) to participate in mainstream society, our results demonstrate that it is crucial to view the inclusion of people with disabilities as a collective issue needing to be addressed cooperatively. If we do not want disability to be seen as the disturbing and demanding reality of a minority of older people but as something both normal in an aging trajectory and specific to certain people, if we wish to achieve participation not just for highly functional or elite seniors but for all older people regardless of their state of health, there is work to be done.

In CJR, the next step will be the implementation of practical guidelines for all activities, to help create a more inclusive environment. Following the analysis of these results, the members

of the research project decided to focus on four issues: clarifying the mission and policies of the organization to ensure consistency between theory and practice; raising awareness of disability and its impacts in individual and collective terms; offering improved coaching to activity managers to help them plan and achieve their activity; and develop tools to guarantee that all members will feel welcomed in all activities. In the Fall 2016, intervention programs tackling those issues will be tested in five activities and evaluated thanks to a case study methodology. The conclusions will lead to the elaboration of the practical guidelines, supporting a proper implementation of the policy, respectful of the organization's realities and people.

Of course, older people with disabilities must be at the heart of this agenda for change, not as a special group but as equal older citizens looking for meaningful involvement or activities. Undoubtedly, this implies deconstructing dominant models of aging – or anti-aging - focusing on health and achievement, and seeking to contribute to what we could call the politics of solidarity in old age.

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