



Strengths and limitations of the Inclusive Society research model: an autoethnography

Alexandra Tessier, Karine Latulippe, François Routhier, Émilie Raymond, David Fiset, Maëlle Corcuff & Philippe S. Archambault

To cite this article: Alexandra Tessier, Karine Latulippe, François Routhier, Émilie Raymond, David Fiset, Maëlle Corcuff & Philippe S. Archambault (2023): Strengths and limitations of the Inclusive Society research model: an autoethnography, *Disability and Rehabilitation*, DOI: [10.1080/09638288.2023.2219067](https://doi.org/10.1080/09638288.2023.2219067)

To link to this article: <https://doi.org/10.1080/09638288.2023.2219067>



Published online: 05 Jun 2023.



Submit your article to this journal [↗](#)



Article views: 30



View related articles [↗](#)



View Crossmark data [↗](#)

Strengths and limitations of the Inclusive Society research model: an autoethnography

Alexandra Tessier^{a,b,c,*} , Karine Latulippe^{a,b,c,*} , François Routhier^{d,e,f} , Émilie Raymond^{e,f,g},
David Fiset^{e,f}, Maëlle Corcuff^{d,e,f} and Philippe S. Archambault^{a,b,c} 

^aSchool of Physical and Occupational Therapy, McGill University, Montreal, Canada; ^bCentre for Interdisciplinary Research in Rehabilitation, Montreal, Canada; ^cInstitut universitaire sur la réadaptation en déficience physique de Montréal, Montreal, Canada; ^dDepartment of Rehabilitation, Université Laval, Québec, Canada; ^eCentre interdisciplinaire de recherche en réadaptation et intégration sociale, Québec, Canada; ^fCentre intégré universitaire de santé et de services sociaux de la Capitale-Nationale, Québec, Canada; ^gSchool of Social Work and Criminology, Université Laval, Québec, Canada

ABSTRACT

Purpose: The *Inclusive Society* partnership research model aims to promote change in society for people with disabilities by supporting research teams composed of researchers and partner organizations. The objective of this article is to identify the strengths and limitations of this research model.

Material and methods: An autoethnography approach was used. Thematic analysis of four methods was undertaken: semi-directed interviews with members of the research teams funded by *Inclusive Society* (researchers, partners), a focus group with the *Inclusive Society's* intersectoral collaboration agents, their logbooks, and *Inclusive Society's* annual reports.

Results: Strengths and limitations of the *Inclusive Society* model were identified through their networking activities, the role and support of the intersectoral collaboration agents and the partnership research program.

Conclusions: Networking activities are an essential element of *Inclusive Society*. They are indispensable for composing intersectoral research teams that will work on answering needs of people with disabilities. Intersectoral collaboration agents are also a strength of the model, but their role could be clarified to better frame what tasks are in their scope of practice and what the research teams could ask from them. Finally, the research program eligibility criteria could be improved to support, among others, the projects' appropriation phases.

> IMPLICATIONS FOR REHABILITATION

- Networking activities stimulate the creation of intersectoral research teams centered on answering the needs of people with disabilities that are identified in the field
- Hired facilitators can play an important role in the emergence of research teams, merging the academic and non-academic worlds, and supporting the teams during their research project
- In participatory research projects, some funding should be reserved to support the partner organization's participation and the appropriation phase of the research projects

ARTICLE HISTORY

Received 22 July 2022
Revised 19 May 2023
Accepted 21 May 2023

KEYWORDS

Partnership research;
participatory research;
handicap;
disabilities;
inclusion;
autoethnography;
research model

Introduction

In Quebec (Canada), 16.1% of the population aged 15 years and older has at least one disability [1]. For the world's population at large, the figure is 15% [2]. Furthermore, each person is likely to experience some form of disability (temporary or not) at some point in their life [2]. All people with disabilities (PWD) are also likely to experience social exclusion in activities related to health, leisure, work, housing, culture, and education [3]. PWD who have been exposed to discrimination and social exclusion may also have experienced reduced well-being and an increased likelihood of suicide [3]. Within a social justice perspective, individuals have a responsibility to respect PWD and to take into consideration their needs [4]. Consequently, a community that enables PWD's enjoyment of their rights and full social participation by ensuring that they have access to physical, social, economic, technological,

and cultural environments, as well as health and education services, can be defined as an inclusive society [5]. The "Toward a More Inclusive Society," or simply "Inclusive Society" (IS) research model is an interdisciplinary and community partnership aimed at producing concrete changes in various aspects of the lives of PWD, supporting the transformation of the associated ecosystems (family caregivers, community organizations, public organizations) and implementing solutions to reduce the environmental and social obstacles that PWD encounter in everyday life.

Following the first projects developed in the framework of the IS research model, we conducted an initial study to identify the challenges and facilitators of partnership research within our partner community [6]. We have learned that working effectively with a variety of stakeholders requires creating the right conditions for the project from the start. This includes explicitly determining among team members how the team will function, clarifying the

project objectives and the expectations of each party, and agreeing on a realistic action plan. Subsequently, during project implementation, it is important to ensure shared leadership, to use agreed-upon communication and conflict resolution methods, and to adequately recognize each team member's expertise. At the end of a partnership research project, it is essential to spend time implementing the project's results, to ensure that they are useful to the partners. This study also revealed a number of themes (such as the role of intersectoral collaboration agents) that were not directly related to partnership research and to our research questions, but to the functioning of the IS model itself. Considering that the models or structures of partnership research form the backdrop of the partnership dynamic and can have a significant impact on outcomes [7], we felt it was essential to reflect on our own model and explore how it supports partnership research and how we can improve it to reduce the challenges of partnership research. This gave us the opportunity to reflect and take a critical look at our own operating model and its own effect on building an inclusive society.

There is growing, but still limited, literature on models of partnership research between universities and stakeholders around societal issues [8], specifically in the area of disability. Given the importance of community engagement in partnership research, and the time and money invested, sharing knowledge and experience on partnership research models is valuable and necessary [8]. The increased use of partnership research models requires a critical examination of how this type of research is operationalized to understand what is possible, improve existing models, and base future models on experience [7,9]. For example, Kegler et al. [8] shared their experience with three partnership research models. They learned that using small grants stimulates research and partnership building, but that the expected deliverables remain modest. It was at the \$30,000 grant level that they observed community impact. They also learned that it can be useful to coach academics in partnership research without this coaching being perceived as an inference in the project.

Research objective

Consistent with the need to base partnership research on experienced, effective models and to improve them, the objective of this article is to identify and share the strengths and limitations of Inclusive Society (IS) research model, as experienced by IS actors.

Materials and methods

Research design

This study was conducted within an autoethnographic perspective, an approach aimed at understanding a lived situation through a critical and reflexive analysis of the researcher's experience. We believe that our approach could have been based initially on an evaluative inquiry for program improvement. However, our initial goal was really to identify the facilitators and barriers to partnership research. In analyzing the data, we found themes that were related not to partnership research in the broadest sense, but to our operational model of partnership research. This led us to reflect on the interdependence between our research model and partnership research as it is experienced within SI. The autoethnography then became a way to share the fruit of our reflections on our model, the values and the research culture that result from it, and their effects on the partnership research that takes

place there. Autoethnography produces a personal narrative intended to provoke reflection in others. In this sense, and in light of its strengths and limitations, the IS experience might inspire similar initiatives [10]. Jiang et al. [11] outline five key features of autoethnography: 1) the authors must have complete member researcher status (which is the case here); 2) the reflective process is based on the desire to better understand oneself by looking at one's actions and environment; 3) the researcher must situate the ethnographic data within the framework of their personal experience and meaning-making; 4) the process involves a dialogue with informants other than self; 5) it is not only a personal experience, but a theoretical understanding of a larger phenomenon. In this sense, we have attempted to write in accordance with the methodology in a more narrative manner, written in the third person plural in the representation of us as authors, and incorporated more reflection from the team into the results.

Research team

The authors of this article are all members of the IS initiative. PA (2017-) and FR (2021-) are IS co-directors. DF acted as ICA with IS at the time of the study (2017–2021). ER is co-investigator in the current project and has previously received IS funding for another research project. KL and AT are both involved in partnership research projects as postdoctoral fellows; they carried out the analysis and interpretation of data regarding IS research for the purpose of this study. Finally, MC, a Ph.D. candidate, worked as a research professional with IS at the time of the study.

Data collection and analysis

Insofar as this autoethnography is based on a series of themes that emerged during our initial study [6], it builds on the methods used in that prior research. A brief summary follows.

Three types of participants were recruited for this study: 1) the three IS intersectoral collaboration agents, 2) researchers of IS-funded projects, and 3) the partners of these projects. The study was based on four data collection methods: individual semi-structured interviews, focus groups, ICA logbooks, and IS annual reports. The ICAs conducted individual semi-structured interviews with researchers and partners of IS-funded research projects for the 2017–2020 period. The first round of interviews took place during the projects' initial stages (2018–2019) and the second round during their final stages (winter 2020). Interviews were conducted by phone or video conference and lasted on average 30 min. The ICAs took notes on the responses. A total of 46 interviews were conducted (23 for each round of interviews) including 8 partners and 15 researchers. The latter were experts from various research sectors ($n=6$ in health, $n=5$ in society and culture, $n=4$ in nature and technology). Their experience in participatory research also varied between no experience ($n=7$), 3 to 10 years of experience ($n=7$), and 10+ years of experience ($n=9$). Second, a focus group, facilitated by a postdoctoral fellow (KL), was held with the three ICAs (two women and one man). The focus group lasted approximately two hours and the data from the audio recording was condensed and verified by the three participants. Third, the digital logbooks completed over the course of a year by the ICAs to collect their reflections on the research projects they monitored were analyzed. ICAs' experience in partnership research ranged from 3 to 10 years. Specifically, for this autoethnography, the two postdoctoral fellows combed through the IS annual reports (2017–2018, 2018–2019, 2019–2020),

available on the IS website [9] to identify information that supported the data collected through other methods. The interview, focus group, and logbook data were thematically analyzed [12]. First, the interviews were analyzed by an ICA in a Word document that presented and described the different themes discussed in the interviews. Subsequently, the focus group and logbook data were incorporated into the document by the two postdoctoral fellows (KL and AT). The themes were then refined through an iterative process involving five to seven rounds of validation by the postdoctoral fellows and a review by one of the researchers (ER). At this point we became aware of the fact that we had two broad categories of themes: 1) those relating to our initial research question focused on the challenges and facilitating practices of partnership research and 2) those reflecting the strengths and limitations of our model. Finally, the annual reports were examined for other themes but they revealed no new topics.

Results

The strengths and limitations of our model are presented here with respect to the three key components of our model namely, networking activities, ICAs, and the research program. First, let's present our partnership research model.

Description of our Inclusive Society partnership research model

The Inclusive Society initiative grew out of a desire shared by four organizations—the Réseau provincial de recherche en adaptation-réadaptation (www.repar.ca) [13], the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal [14], the Centre interdisciplinaire de recherche en réadaptation et intégration sociale [15] and the Regroupement stratégique Ingénierie de technologies interactives en réadaptation [16]—to combine their expertise in addressing a number of major societal issues and to involve in the process stakeholders in the adaptation, rehabilitation, social participation, and other related fields, as well as partners from the community, municipal, cultural, industrial, and health sectors [17]. In an effort to find ways to advance research and practice toward an inclusive society, the Initiative conducted a consultation process with various actors involved with PWD and research organizations devoted to adaptation rehabilitation. Among the key factors identified were the use of participatory and “bottom-up” approaches (it means that the identification of needs and issues, as well as the means to address them, comes from the people directly affected by these issues and their ecosystem - in this case, by PWD, their loved ones, and the stakeholders working with them), having an ongoing evaluation process, securing funding to support project success and sustainability, creating new partnerships while consolidating existing ones, involving policy-makers and PWD in projects, knowledge mobilization and co-creation, and finally intersectorality (it means bringing together people from different disciplinary fields or practices on the same research question) [18].

In order to leverage these factors in an integrated manner, our IS initiative proposes a research program based on a participatory approach to knowledge co-construction, more specifically partnership research [19]. All stakeholders are therefore engaged at different stages of the research process to design and apply solutions together with a view to reducing the barriers to social participation faced by PWD. At the heart of the process lie several established principles and values of participatory research such

as creating relationships of trust [20], power sharing within teams [21], understanding the issues at stake, valuing each person's role [22], and reciprocity [23]. The initiative targets four major themes: 1) physical environment and personal mobility, 2) social environment, 3) health and adaptation-rehabilitation, and 4) attitudes, prejudice and discrimination. For example, one of the IS projects is focused on identifying innovative solutions to facilitate the employment of PWD by improving access to public transit [24]. The research team is composed of various stakeholders, including researchers, a transportation company, an organization dedicated to protecting the rights of people with disabilities, a collective specializing in the employment of PWD, and a large national employer.

The IS initiative's operating structure is based on three key components. First, it uses networking activities to engage partners and researchers from different backgrounds and scientific fields. For example, discussions on topics such as parenting and access to employment have been organized since October 2017. Second, the IS structure includes intersectoral collaboration agents (ICA) who support partners and researchers in the ideation process and project implementation, in particular in team building, maintaining relationships, and appropriation of results. Third, the IS Partnership Research Program provides financial, material, and human resources to support projects at different phases of the social innovation process (emergence, experimentation, appropriation). More specifically, selected projects can obtain up to \$25K for a period of 12 to 18 months. The proposed projects must be directly related to the needs of PWD expressed by one or more organizations. They must also be transferable, i.e., allowing for the knowledge gained to be used to promote the social inclusion of PWD in different contexts. The main project partner must be an organization outside the academic and research community. Project outcomes should aim to produce concrete changes in various aspects of the lives of PWD. Projects must also include a plan for the dissemination of the results within the networks of the partner(s) involved and among their collaborators. A midterm progress report and a final report on the project are submitted to IS using an online form. In addition to the main partner, the research teams must be composed of at least two principal investigators, each representing a different scientific sector, i.e., nature and technology, health, or society and culture, in order to meet the intersectorality criterion required for obtaining IS funding.

IS initiative's organizational structure, designed to support the achievement of its mission, includes an assembly of partner members, a forum for discussion and informing partners and their members of IS activities, a community of practice where stakeholders share their experience, a partners' committee which determines the directions and ensures the proper management of the initiative and an executive committee which manages IS's operational activities. Figure 1 presents the different governance bodies of the IS initiative and the relationships between them.

Between 2017 and 2020, more than 27 projects were implemented as part of the IS initiative, involving 84 community partners, 105 researchers, and 38 graduate and postdoctoral students. Following the first funding period (2017–2020), IS's goal for 2020–2023 was to solidify its expertise and develop methodological tools for partnership and intersectoral research [25].

Networking activities

The ICAs and the IS Partners' committee explicitly qualified networking activities as one of the Initiative's strengths as they

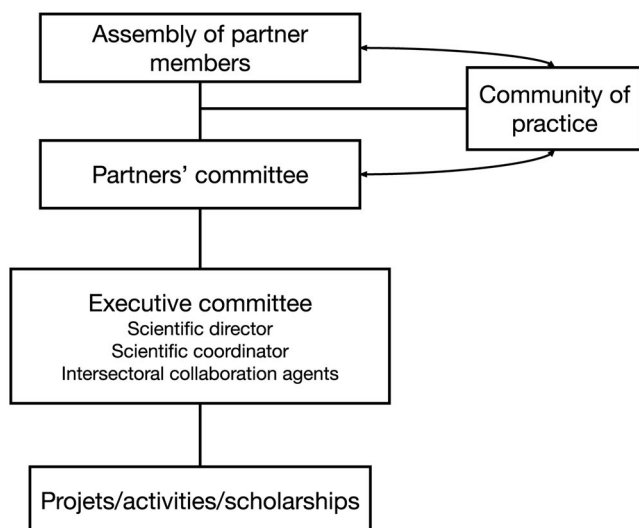


Figure 1. Relationships between Inclusive Society governance bodies.

enabled the ideation that is necessary for identifying needs and building partnership research teams.

IS networking activities have brought researchers and partners together, built collaborative relationships and generated partnerships.

I'm glad to hear that X was able to build collaborative relationships with Y and Z at the 2019 Exchange Forum. (Logbook; ICA 2)

At networking events, participants learned how to create a partnership research team, how to develop an idea into a research project, whom to engage, and how to identify interested parties. We also observed the reinforcement of values shared by the different partners, such as the importance of collective intelligence, the cross-fertilization of knowledge and the recognition of each person's contribution, as well as the importance of developing concrete projects that bring observable changes to the community in the medium term (applied research) during forums. In some cases, ICAs organized meetings between researchers and community partners that were devoted specifically to working on submitting a project. They facilitated these meetings, which seems to have helped to incorporate the various organizations' concerns into the research projects. Moreover, for most of the interviewed teams' projects (5/8), the collaborators met or reconnected at networking events organized by IS or were assisted by ICAs to build a team.

I recently organized three meetings requested by researchers wanting to connect with partners in order to submit a proposal for our 4th competition. The partners seem to appreciate the fact that the researcher travelled to meet them in person. I want to stress that the purpose of the meeting is to allow them to express their needs as an organization in relation to the proposed idea for a project. In all three cases, the researchers found the concerns raised by the partners to be very pertinent and included them in the project. (Logbook; ICA 2)

However, one of the limitations of networking activities is that they are time-consuming for ICAs. The work in the lead-up to the event, the event itself, and the follow-up needed to make sure nothing is lost took a lot of time. In some instances, the ICAs couldn't keep up with team monitoring. However, considering that these activities are incubators for partnership and that the latter is the basis of our epistemological posture, the time invested

appears to us to be profitable. In addition, despite the networking activities, several projects did not get past the ideation stage for lack of researchers to take them on. In these cases, the ICAs tried to find potential funding and researchers to put together a team. Sometimes, they were unable to do more to support the needs expressed for want of available or interested researchers. We are disappointed that partners have taken their time to participate in the activity, sharing their ideas and needs without any concrete results (or projects). What effect might this have on their future participation? Were they disappointed or did they feel that their point was heard and that they had raised awareness? How can we prevent this unwanted outcome from our networking activities?

Another limitation of our IS model according to the ICAs is that the community of practice can be optimized and that it can benefit from improved monitoring tools.

Intersectoral collaboration agents

General appreciation

In general, the presence of ICAs appears to be one of our IS model's strengths. Participants expressed strong appreciation for the role ICAs play and the support they provide. This sentiment is also reflected in the progress reports submitted by the research teams: *"Midterm evaluation of projects is currently underway. The reports we've seen so far note among other things satisfaction with ICAs and that it was reassuring to be getting help from someone."* (Focus group; ICA 2). The researchers and partners were especially appreciative of certain elements of the ICAs' support, namely their proactiveness, such as taking care of logistics (e.g., organizing meetings), which helped to organize teams as projects progressed and increased their effectiveness. By facilitating relationships, ICAs also promoted collaboration and cohesion among team members. Acting as information focal points allowed them to bridge the gap between partners and researchers, but also to pass on knowledge about, among other things, partnership research, the IS initiative, and funding programs or collaboration opportunities. In addition, they helped to demystify the world of research, helping partners to feel more comfortable about expressing their needs.

This was an important aspect for her; feeling comfortable in the research environment that she was unfamiliar with, and she feels that IS contributed to that. (Interview; Partner 2)

The ICAs reported that when they were on the executive committee or on the steering committee for a particular project, they acted as a sounding board or a liaison, but never in a decision-making capacity. They found it useful to be part of these teams because of the significant information flow that took place within them. The ICAs noted that the services they provided that were most used by the teams were organizing meetings, answering questions, facilitating, coaching, and outreach. Many of the researchers in our group have been trained in more conventional approaches to rehabilitation (e.g., conducting a research project as a leader with a few co-investigators more or less active in the project). This is a paradigm shift for us. ICAs support both researchers and partners in the realization of optimal partnership research.

Flexibility of the ICA's role

According to the ICAs, the flexibility they enjoyed in defining their tasks was nonetheless both a strength and a limitation of their role. Their involvement varied depending on the team, the project, and what stage it was at (e.g., initiation, data collection, analysis).

For example, whereas in some teams, ICA involvement was significant in the project development stage and gradually decreased, in others, it was sustained throughout the project. In some cases, ICAs were not at all involved in the project's submission to IS.

When it comes to defining ICA tasks, flexibility is both a strength and a limitation of the IS model. It's a strength insofar as each ICA can work according to their own style and availability, and also allows for a wide range of services. It's also a strength in providing assistance to teams, a reassuring liaison. Each team and project are unique and the ICAs are able to adjust to that in order to achieve the goals. (Focus group; ICA 2)

However, one of the limitations of our model mentioned by the research teams is insufficient definition of the ICA's role as a result of which teams had a poor understanding of the kind of support they could obtain. For example, they were unsure about the ICAs' tasks, the time they could devote to the project, and the support they could provide in terms of coordination versus research assistance. According to some participants, it is desirable that ICAs support the research teams from the beginning to the end of the project; some would have liked more consistent communication with the ICA to help identify the needs of the teams and find ways to meet them, to ensure the projects' progress and plan the next steps. They would have liked more informal follow-up instead of monitoring by means of filling a form (e.g., at midterm).

Doing informal follow-ups, not filling forms! A "Hi, just checking in"... Once the projects were underway, there was less monitoring and it would be nice if it were more frequent, but not through forms to fill out, just a heads-up to let people know where the project is at and plan the next steps. (Interview; Researcher 11)

The ICAs were also uncertain about their tasks, and they perceived this as a limitation of the IS model. For example, they were unsure about whether they should attend certain meetings, where the line between providing support and providing guidance lies, whether they were to offer equal services to different teams and whether performing technical or secondary tasks requested by certain teams was legitimate (e.g., fetching coffee out of courtesy).

A researcher asked me to go look for their poster for the Inclusive Society Exchange Forum on September 28. She often asks me to do these types of tasks (getting coffee and snacks for the meeting, taking care of the technical side...). I don't always know if I should accept to do these tasks. At the same time, it's hard to say no to her and I know that in the end, it frees up the other team members. (Logbook; ICA 2)

We observed that the three people in place were operating in completely different ways without being able to identify one mode of operation as more efficient than another. Is the ICA who helps with less meaningful tasks such as booking a room wasting her time or is she instead developing a trusting relationship with a research team? Also, considering the uniqueness of each project, the varying levels of experience of teams in partnership research, and the leadership styles of team members, how much sense would it make to have a specific job description? On the other hand, we recognize that a little more clarity for members and new ICAs would be helpful.

Intersectoral collaboration agents support in securing project funding

Another strength of the ICAs' involvement in the projects was that they could help the teams to prepare funding applications by reviewing the applications or drafting a letter of support to

partners. The ICAs' position within the IS initiative allowed them to offer advice on both the scientific and partnership aspects of research projects. However, the ICAs were unclear about the scope of the comments they could provide:

I just reviewed a draft of X's application for funding. It's hard to know how far I should go in my comments and suggestions. I spent a fair amount of time on the application (4 hours), trying to provide constructive feedback. The application did not fully reflect the discussion we had had with X and Y. They will go over it again, but I felt it was important to point out to X elements that could be better aligned with the needs expressed by Y. I also commented on the intersectoral aspect (weaker health component) and the impact of social inclusion, which I felt could be strengthened. (Logbook; ICA 2)

How extensively do we comment on projects considering they will be evaluated by someone else? (Focus group; ICA 2)

In addition to helping the teams draft their funding applications, the ICAs attended the IS project evaluation committee as observers. This allowed them to synthesize the comments made by the evaluation committee and to convey them to the teams. The ICAs said they can provide pertinent explanations about the projects they monitor during evaluation committee sessions but that this might be unfair to other teams that do not receive assistance. Moreover, they felt there is a risk of bias because they are familiar with the strengths and weaknesses of some projects and would tend to highlight their strengths. Consequently, in the ICAs' opinion, the discomfort they experienced as a result of having to relay the evaluation committee's comments on issues they had previously commented on is a limitation of their role.

"ICA 2: Maybe I should have told them that, did I forget something

ICA 1: did I miscommunicate the information..."
(Focus group; ICA 1 & 2).

In addition, the ICAs felt they had a responsibility to the teams, in particular to find alternative solutions for projects for which funding or a second researcher had not been secured. They explained that it was part of their job to leave no one behind and to continue to support projects that failed to obtain IS funding. They see the IS initiative as more than a source of funding. Perhaps at the project evaluation stage with the evaluation committee, the role of ICAs is not necessary. Considering the discomfort felt, which we understand and that they have already supported the teams in the preparation of the application, this contribution should be reconsidered.

The Inclusive Society Partnership Research Program

Amount of the funding provided by Inclusive Society

The ICAs view the IS funding structure as a strength of our model and one that should be maintained because it provides teams with a common goal and supports project completion. In interviews, participants mentioned being impressed with what they were able to achieve with a \$25,000 budget: *"provides an opportunity to develop projects of this type, which are usually difficult to fund."* (Interview; Researcher 6). This funding also makes it possible to compensate partners for taking time away from their daily activities in order to participate in the projects and to meet the expectations of those who do not wish to work for free. It has been observed that paying some team members can influence team composition. One ICA received a call from a partner who said she was tired of working for free. The ICA told her that it was possible to request partner release time funds and that she should talk to the researchers about it. Which she did and it worked.

Although the funding structure was deemed to be one of our model's strengths, some limitations pertaining to project funding were nonetheless identified. The amount of IS funding was considered by some teams to be insufficient for conducting partnership research. While recognizing that it was a good start, some participants noted that more money was needed, among other things, to allow for the development of solutions and to tailor projects to the partners' needs. Insofar as looking for funding is time-consuming, organizations would benefit from increased support in putting together financing plans. Participants also mentioned that organizations should be better informed about the possibility of obtaining financial support. Researchers also feel that partnership research requires a great deal of energy and commitment on their part, but that little money is available to support project coordination. We believe that partnership research takes more time than conventional research during the creation of the project and during its implementation since more communication and exchanges are necessary. However, we believe that knowledge mobilization is faster in the sense that the project partners are already aware of the results and, we hope, to use them in their practice.

Delayed release of research funds

Another limitation identified in the IS funding structure was the delayed release of funds to research teams. Although we had little control over this aspect, delays in disbursement resulted in problems with paying partners and students, caused stress and impatience, and ultimately slowed down the research projects.

Team X got their notice that IS funds had been awarded on 2017-11-09 and did not receive them until... 2019-03-04! The story repeats with project Y, delays are hurting the partnership research; the project is delayed, \$ difficulties for partner release time funds, students, etc. creating stress within the team, and impatience. I would even say that it discredits us, the Initiative, even if we're not responsible for these delays. But surely, we could do more? Do better? Have a better strategy to deal with this problem that dampens our morale (that of the affected teams and ours since we've been running around in circles on this issue). (Logbook; ICA 1)

Obstacles to the appropriation phase of research projects

Some limitations of our model seem to preclude appropriation of IS-supported partnership research projects.

First, the innovation criterion required to obtain IS funding is less obvious in projects focusing solely on knowledge appropriation. Such projects therefore received less funding.

In our social innovation process, there are three phases: emergence, experimentation and appropriation. In theory, we fund projects in these three spheres. Except that we haven't really funded projects that only concern the appropriation phase because there is often no experimentation or innovation, which is a criterion that we highly value. What works for the partner in the appropriation phase is not necessarily innovative. (Focus group; ICA 2)

In addition, the intersectorality criterion may have been detrimental to appropriation-focused projects because it is not necessarily present at that stage and projects that did not meet this condition were not eligible.

However, another criterion that is detrimental is intersectorality; this is more difficult to achieve at the appropriation phase and not always necessary. [...] If the appropriation phase is linked to a technology, the technology development phase has already been completed and is no longer represented in the appropriation phase. So it's no longer considered intersectoral. (Focus group; ICA 3)

For a project that is entirely in the appropriation phase, the two criteria, innovation and intersectorality, become contradictory. (Focus group; ICA 2)

Third, the 18-month timeframe, with a budget of \$25,000, was considered too short to see projects through the appropriation phase.

"ICA 3: Within an ideal perspective, there is also a post-project phase, the appropriation phase. Ideally, we'd get to this point where we provide support for the appropriation of the results within the local context.

ICA 2: Currently, we want this to be part of the project, but with projects limited to 18 months and \$25,000, it's harder. The current projects are not there yet."

(Focus group; ICA 2 & 3)

To encourage the development of partnership research projects including an appropriation phase, the ICAs suggested creating a funding program specific to projects in that phase. This would allow us to quantify and provide the resources needed for their implementation and completion and to fund projects over a longer period of time which would facilitate appropriation of data.

Obstacles to research team building

The intersectorality criterion, i.e., participation of researchers from two distinct fields, coupled with the requirement that at least one researcher be part of one of the IS initiative's four partner research networks in order to obtain funding sometimes acts as a constraint in team building and therefore constitutes a limitation of our model. As a result, ICAs are forced to devote a significant amount of time looking for researchers that meet both the needs of the field and the funding criteria. In addition, this creates a risk that researchers recruit a second researcher solely to meet the intersectorality criterion, which would unfortunately lead to a lack of shared leadership between researchers since one of them would be virtually absent from the project.

"ICA 1: The IS platform has an Achilles heel: researchers have to belong to one of four networks.

ICA 3: We've already worked with all of them, since they're often the same.

ICA 2: The requirement of intersectoral, on the one hand, and picking a researcher from four networks on the other makes no sense. There are researchers elsewhere.

ICA 1: We were able to comply with it for three years but if the IS initiative continues, it will get harder."

(Focus group; ICA 1,2, & 3)

Lastly, the participants noted that involvement of people with disabilities is limited. If a team really wants to follow the 'for and with' principle, it must be representative. This aspect has troubled the authors of this article. Rich discussions followed. IS could be seen in itself as a micro-society. Is our micro-society inclusive? What place do PWD have in our own process? We believe that the involvement of PWD in projects that concern them is essential and is part of an inclusive society. By making this a mandatory funding criterion, we feared that people would be "instrumentalized". By not making it mandatory, it seems to us that we are endorsing the fact that partners (e.g., worker who supports PWDs, but does not have disabilities himself) can represent PWD, which we question to some extent. We will come back to this aspect in the discussion.

Sustainability of the Inclusive Society initiative

Finally, the ephemeral nature of the IS platform, due to its funding which must be renewed every three years, was identified as a

limitation of our model by the ICAs. In their view, if IS funding were to become permanent, ICA positions could be supplemented by communication and partnership research experts.

"ICA 2: We are not experts in communication..."

ICA 1: We improve, but...

ICA 2: even though we can manage a newsletter and a twitter account, for example we are not experts in this area

[...]

ICA 3: Within a sustainability perspective, instead of hiring an ICA, one could hire a communications officer and an expert in partnership research. [...] Without being too domineering, an expert in partnership research can help to better steer, guide and support the teams in partnership research."
(Focus group; ICA 1, 2, & 3)

Discussion

Our purpose in engaging in this autoethnographic exercise was to draw recommendations for ourselves, but also for researchers with an interest in partnership research wishing to develop a research structure that supports it. We will present these recommendations in relation to the identified strengths and limitations of our model and in relation to the three key components of the IS initiative: 1) networking activities, 2) ICAs, and 3) the research program.

First, albeit time-consuming for ICAs, networking activities are one of our partnership research model's strengths. They make it possible to identify needs, to put researchers in contact with partners in the field, and to build research teams to meet these needs. They are the cornerstone of partnership research [26] and, in our opinion, essential to our model. As regards the community of practice, our thinking has evolved since we conducted our data collection. After revisiting the issue, our assumption was that the community of practice, as it was in 2017–2020, addressed too many topics, which may have hindered discussion. Few people had an interest in any particular topic. Multiple communities of practice might have been needed at the risk of not achieving critical mass. As a result, in 2021, we decided to develop our presence on social media instead of a community of practice, where we included a knowledge transfer component and offered our networking activities, whose definition is similar to that of communities of practice, i.e., exchange, sharing and learning from each other [27]. We will continue these activities and recommend that those interested in developing a partnership research model include this type of activity in their agenda.

The presence of ICAs is also a strength in our model. The help they provide to teams by assisting them to draft funding applications and by monitoring their project has supported work progress and facilitated relationships between team members. Renaud [28] argues that the [mobilization] agent is indeed a key element of partnership research insofar as they "bridge the partners' cultural and organizational worlds [our translation]" (p.97). According to her, their role also includes "promoting appropriation of research data and its integration into organizations [our translation]" (p.97). This aspect of the ICAs' role was not highlighted in our process. In fact, since ICA support is variable in terms of duration, it is quite possible that a number of teams were not supported until they reached this stage. Moreover, as a facilitating practice, the participants in our previous study suggested increasing support and coaching to promote the appropriation of results in the local context [6]. Furthermore, we believe that the flexibility

of the ICAs' role should be maintained in order to allow them the freedom to focus their help where teams have needs. However, research teams and ICAs would benefit from clarifying the ICAs' job descriptions. This would also facilitate ICA integration into teams. To the extent that research teams naturally have research expertise (with the researcher) as well as content expertise related to the research subject (with the partners), we believe it is appropriate to focus the ICAs' role where the challenges are greatest in partnership research, namely the intersection between the academic and intervention fields [29]. We realize that the main challenges for research teams are developing acting-together skills—the "collective capacity to co-construct, to blend expertise and to act through cross-sector collaboration" [30]—and collective intelligence, i.e., the ability of a group to act on a social issue on the basis of a process of interaction and collective reflection involving dialogue and genuine collaboration in order to address complexity differently [6,31]. As Roy and Prévost [32] put it, "it is from the clash of different points of view of participants with diverse interests, including that of the researchers [...] that a shared understanding of the issue can emerge [our translation]" (p.138). In this sense, the ICAs' role could evolve into that of a facilitator of the partnership research process. This might mean stepping away from the tasks of reviewing funding applications and coordinating certain teams and research activities to focus instead on assisting teams in clarifying common intent (needs, expectations, roles), communication within the team, problem solving, and power sharing, among others [29]. To these can be added supporting implementation of the results in the local context.

Our third key component, the IS funding program, supports project implementation by financing projects that are otherwise unlikely to obtain funding, including from major research granting agencies. Two elements merit discussion, however. The first is related to the intersectorality and innovation eligibility criteria in the IS program. The intersectorality criterion, i.e., the dual condition that the two researchers belong to distinct research fields and that at least one be a member of one of the four IS partner research networks, limits the pool of researchers available to meet the needs of the partners and increases the risk that researcher appointment for a project will be instrumentalized. This criterion is justified by the great complexity of the IS initiative's goal, which requires: "research contributions and approaches that extend beyond multidisciplinary and inevitably call for intersectoral research, by bringing together expertise from more than one of the major science sectors in Quebec (Health, Humanities and Social Sciences, Natural Sciences and Engineering) [our translation]" [18, p.4]. We understand the importance given to this aspect by the initiators of IS, but should it not be a strength rather than a limitation when it comes to meeting partners' needs? Can we consider putting the necessary effort into creating teams that have these characteristics, without making eligibility for funding conditional thereon in the event where this proves impossible? The intersectorality criterion is currently under review. As for the innovation criterion, it has its place because it is at the very heart of our model, as does knowledge mobilization. Moreover, in the period between data collection and the drafting of this article, a new collaboration with the Saputo Foundation has made it possible to increase funding to 35K, of which 10K is dedicated to the appropriation of the results and the implementation of a solution by partners.

Finally, we would like to address one last point that we consider crucial, but also complex. The initiators of IS have given great importance to the representation of PWD within projects (through community, public and private organizations) by

conditioning funding on such representation. However, to the degree that IS's mission is to produce concrete changes in various aspects of the lives of PWD, we might wonder why members of these communities are not invited to participate directly in discussion forums. As framed by Eyraud et al. [33, p.9], the question is "how can we discuss and/or decide democratically on actions concerning people whose participation is restricted [our translation]?" The involvement of organizations working with PWD in research projects is pertinent since IS also aims to transform the ecosystem around these populations. Likewise, we must consider the need to give PWD a seat at the discussion table so that projects can benefit from their valuable contribution. A number of IS projects involve PWD (e.g., co-design of an assistive internet navigation device for people with visual impairments) [9] but not as a condition to receive funding. Paradoxically, although such a criterion could be supportive of PWD involvement in the projects if it were to become a requirement tied to funding, it could also cause PWD to become vulnerable to instrumentalization, in the same manner as the intersectorality criteria concerning researchers; it could even lead to the exclusion of PWD [33]. There is a major reflection to be had here. An inclusive society should not have to impose the contribution of PWD in projects that concern them. This contribution should be inherent to the values of research and project teams. It might be pertinent to entrust ICAs with the tasks of raising awareness of the importance of PWD engagement in projects and ensuring their full and meaningful participation.

Strengths and limitations of this autoethnography

We have identified the strengths and limitations of our study in reference to the five standards for judging the quality of an autoethnography in the field of health research outlined by Chang [34]: 1) use of authentic and trustworthy data, 2) reliable research process, 3) ethical process in relation to self and others, 4) socio-cultural analysis and interpretation, and 5) scientific contribution. As regards the first standard, Chang [34] argues that using a variety of data collection methods and sources supports the criterion of authenticity and trust. In this sense, our study relies on four data collection methods (logbooks, focus groups, semi-structured interviews, and IS annual reports) and three data sources (ICAs, researchers, and IS partner members). Chang [34] ties process reliability to the transparency of the study and its presentation as well as the reflexivity of the authors regarding the research process. We have tried to describe as extensively as possible the context and process of the study and our own reflections on the research results. The third quality standard refers to ethics toward self and others. Naturally, we obtained ethical approval before conducting this study and all participating researchers and partners signed a consent form. However, the purpose of this research was initially to produce a case study. It wasn't until we began analyzing the results and emerging themes that we became aware of the fact that a substantial amount of data reflected lessons learned from the experience of our own model and that the resulting reflections were characteristic of an autoethnography. Consequently, the authors of this article, who became participants in the study, have not expressed prior consent. Tolich [35] disapproves of retrospectively seeking consent from participants in an autoethnography, placing them in a potentially coercive position following the writing of the article. Although we fail to comply with this recommendation, we nonetheless forwarded this article to the three ICAs who were most concerned by the research topic, in addition to the co-authors,

to ensure that they were comfortable with the data presented. Minor changes were made as a result of their comments. The fourth standard, sociocultural analysis and interpretation, relates to the foundation of ethnography which is to address the socio-cultural meaning of human experience. The thematic analysis used highlighted the strengths and limitations of our model. While the analysis itself was not about IS culture, the data produced is necessarily associated with the initiative's singularity, which implicitly involves a culture of partnership research, interdisciplinarity and intersectorality, and relates to a specific way of approaching research. In this sense, this article reflects the sociocultural significations not of the autoethnographers per se, but of the entity that is IS. Finally, the fifth standard refers to the value of the contribution to the scientific community and research transferability. Although the context is specific to our model, we believe that it can inspire other partnership research initiatives. We would have liked to make more connections to similar studies or models, but despite a scoping review of partnership research (forthcoming), we did not find any models that are comparable to IS in the field of disability. However, we were able to draw on articles that discuss partnership research.

Conclusion

After three years of IS operation, we wanted to identify the strengths and limitations of our partnership research model by taking an autoethnographic look at it. As a result, we have been able to ascertain that networking activities, ICAs and the funding structure are strong elements of our model insofar as they promote partnership research projects involving collaboration between academia and civil society with a view to meeting the needs of non-academic stakeholders. Nonetheless, each of these components can be optimized to improve IS functioning. To this end, we recommend, among other things, redirecting the role of ICAs toward focusing on facilitating partnership research and fulfilling funding criteria in support of projects at any stage of the social innovation process that are aimed at meeting partners' needs. We would also like to see greater participation of PWD in research projects. These changes can allow for the implementation of a partnership research model that better meets the needs of PWD while facilitating even more the collaboration between academic and non-academic actors. This would improve IS's capacity to support researchers in a context of partnership and to mobilize a vast network of diversified partners involved in research. As a result, IS would be contributing to a genuine citizen mobilization for research aimed at bringing about an inclusive society.

Acknowledgements

Supported by the Réseau provincial de recherche en adaptation-réadaptation (REPAR), the Ingénierie de technologies interactives en réadaptation (INTER) strategic cluster, the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR), and the Centre interdisciplinaire de recherche en réadaptation et intégration sociale (Cirris), the Inclusive Society initiative is funded by the Fonds de recherche du Québec (2017-2023). François Routhier is a senior research fellow with the Fonds de recherche du Québec - Santé. Maëlle Corcuff expresses her gratitude to the Fonds de recherche du Québec-Société culture for the PhD scholarship she was awarded. Alexandra Tessier is supported by a postdoctoral fellowship from CRIR and REPAR. Karine Latulippe is supported by the Canadian Institutes of Health

Research and the Fonds de recherche du Québec - Santé. The team would like to thank Fabienne Boursiquot and Émilie Blackburn for their involvement at different stages of this research project.

Ethical approval

This research was assessed and approved by the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal Research Ethics Board. All participants gave their written informed consent.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by the Fonds de Recherche du Québec.

ORCID

Alexandra Tessier  <http://orcid.org/0000-0002-0178-421X>
 Karine Latulippe  <http://orcid.org/0000-0001-7998-6498>
 François Routhier  <http://orcid.org/0000-0002-5458-6233>
 Philippe S. Archambault  <http://orcid.org/0000-0002-8656-4477>

References

- [1] Statistique Canada. Enquête canadienne sur l'incapacité (ECI) [Internet]. 2019. [cited 2022 Apr 28]. Available from: https://www23.statcan.gc.ca/imdb/p2SV_f.pl?Function=getSurvey&DDS=3251.
- [2] World Health Organisation. Handicap et santé Internet 2023. [cited 2022 Apr 28]. Available from: <https://www.who.int/fr/news-room/fact-sheets/detail/disability-and-health>.
- [3] Akyol Güner T, Das Gecim GY. Effects of social exclusion on psychological-well-being and suicidal possibilities among people with physical disabilities. *OMEGA- Journal of Death and Dying*. 2021;302228211051819.
- [4] Hammel J, Magasi S, Heinemann A, et al. What does participation mean? An insider perspective from people with disabilities. *Disabil Rehabil*. 2008;30(19):1445–1460.
- [5] Société inclusive. Rapport annuel de l'initiative intersectorielle Vers une société québécoise plus inclusive. 2019.
- [6] Latulippe K, Tessier A, Routhier F, et al. Facilitators and challenges in partnership research aimed at improving social inclusion of persons with disabilities. *Disabil Rehabil*. 2023;1–12. DOI:10.1080/09638288.2023.2188264
- [7] Oetzel JG, Wallerstein N, Duran B, et al. Impact of participatory health research: a test of the community-based participatory research conceptual model. *Biomed Res Int*. 2018;2018:1–12.
- [8] Kegler MC, Blumenthal DS, Akintobi TH, et al. Lessons learned from three models that use small grants for building academic-community partnerships for research. *J Health Care Poor Underserved*. 2016;27(2):527–548.
- [9] Lincoln AK, Borg R, Delman J. Developing a community-based participatory research model to engage transition age youth using mental health service in research. *Fam Community Health*. 2015;38(1):87–97.
- [10] Marshall C, Rossman GB, Blanco G. *Designing qualitative research*. 7th edition. Los Angeles: Sage Publications; 2022.
- [11] Jiang L-J. Conducting collaborative action research: challenges and coping strategies. In: Tsang KK, Liu D, Hong Y, editors. *Chall Oppor Qual Res* [Internet]. Singapore: Springer Singapore; 2019. [cited 2022 Apr 28]. p. 111–123. Available from: [10.1007/978-981-13-5811-1_9](https://doi.org/10.1007/978-981-13-5811-1_9).
- [12] Paillé P, Mucchielli A. *L'analyse qualitative en sciences humaines et sociales*. 3e édition. Paris: Armand Colin; 2012.
- [13] REPAR Réseau provincial de recherche en adaptation-réadaptation. [Internet]. Montreal (QC): [cited 2023 May 18]. Available from: <https://repar.ca/>.
- [14] CRIR Centre de recherche interdisciplinaire en réadaptation du Montréal métropolitain. [Internet]. Montréal (QC): [cited 2023 May 18]. Available from: <https://www.crir.ca>.
- [15] Cirris Centre interdisciplinaire de recherche en réadaptation et en intégration sociale [Internet]. Quebec (QC): [cited 2023 May 18]. Available from: <https://www.cirris.ulaval.ca/>.
- [16] INTER-Regroupement INTER [Internet]. Sherbrooke (Qc): [cited 2023. May 18]. Available from: <https://regroupementinter.com>.
- [17] Société inclusive – L'innovation sociale pour favoriser la création d'environnements physiques et sociaux plus inclusifs [Internet]. [cited 2022 Apr 28]. Available from: <https://societeinclusive.ca/>.
- [18] Kehayia E, Michaud F, Nadeau S, et al. *L'innovation sociale pour favoriser la création d'environnements physiques et sociaux plus inclusifs*. 2016.
- [19] Hoekstra F, Mrklas KJ, Khan M, et al. A review of reviews on principles, strategies, outcomes and impacts of research partnerships approaches: a first step in synthesising the research partnership literature. *Health Res Policy Syst*. 2020;18(1):51.
- [20] Baquet CR, Bromwell JL, Hall MB, et al. Rural community-academic partnership model for community engagement and partnered research. *Prog Community Health Partnersh*. 2013;7(3):281–290.
- [21] Belleau H. De la mobilisation des connaissances au partenariat de recherche. Le cas du "portrait des jeunes du quartier Bordeaux Cartierville" à Montréal. *SociologieS* [Internet]. 2011 [cited 2022 Jul 19]. Available from: <https://journals.openedition.org/sociologies/3730>.
- [22] Bussièrès D, Caillouette J, Fontan M, et al. *La recherche partenariale au CRISES*. Les Cahiers du CRISES; 2013.
- [23] Andrews JO, Newman SD, Meadows O, et al. Partnership readiness for community-based participatory research. *Health Educ Res*. 2012;27(4):555–571.
- [24] Tessier A, Clément M-A, Gibus M, et al. Favoriser l'emploi des personnes en situation de handicap par l'accès au transport collectif : état des connaissances et résultats préliminaires d'une étude qualitative. Montreal (QC), Canada; 2022.
- [25] Société inclusive Rapport annuel de l'initiative intersectorielle Vers une société québécoise plus inclusive. Montreal (QC). 2020.
- [26] Bussièrès D. *La recherche partenariale: d'un espace de recherche à la coconstruction de connaissances*. [dissertation]. Montreal (QC): Université du Québec à Montréal 2018.
- [27] Lave J, Wenger E. *Situated learning: legitimate peripheral participation*. Cambridge (UK): Cambridge University Press; 1991.
- [28] Renaud L. *Modélisation du processus de la recherche participative*. *communiquer*. 2020;30(3):89–104.
- [29] Tremblay D-G, Demers G. Les recherches partenariales/collaboratives: peut-on simultanément théoriser et agir? *rs*. 2018;59(1–2):99–120.
- [30] Communagir. *Chantier sur le développement des compétences. Les compétences essentielles de l'agir-ensemble*. Montreal (QC); 2014.
- [31] Durand C. *L'art de faire émerger l'intelligence collective comme processus de changement émergent* [master's thesis].

- Montréal (QC): Université du Québec à Montréal 2011.
- [32] Roy M, Prévost P. La recherche-action: origines, caractéristiques et implications de son utilisation dans les sciences de la gestion. *Rech Qual.* 2013;32(2):129–151.
- [33] Eyraud B, Saetta S, Tartour T. Rendre effective la participation des personnes en situation de handicap. *Participations: rev de sciences soc sur la démocratie et la citoyenneté.* 2018;N° 22(3):5–28.
- [34] Chang H. Autoethnography in health research: growing pains? *Qual Health Res.* 2016;26(4):443–451.
- [35] Tolich M. A critique of current practice: ten foundational guidelines for autoethnographers. *Qual Health Res.* 2010;20(12):1599–1610.