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Title: Analyzing roles, barriers, and supports of co-researches in an inclusive research

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## Abstract

**Background:** Current research demands we rethink the roles of people with intellectual disabilities in the research that affects them. The paradigm of inclusive research responds to this need. Although specialized literature is progressively adopting a more inclusive research approach, the study of roles and relationships within inclusive research and reflections on the process of doing participatory research has received little attention. From a qualitative approach and a participatory action research framework this study aims to: (1) report the experience of involving adults with intellectual disabilities in an inclusive research, and their improvements in terms of developed competencies; (2) identify their perceived roles as researchers, and (3) describe their perceived barriers and facilitators during the research process. **Methods:** This study describes the experiences of 11 adults with intellectual disabilities who participated in a project aimed at evaluating the cognitive accessibility of public spaces and services in a Chilean city for 14 months. **Findings:** Different roles emerged, ranging from apprentices to experts by experience, and were adopted to different extent by co-researchers as the process evolved. Co-researchers developed conceptual, procedural, and attitudinal skills. They also identified contextual and personal barriers as well as facilitators consisting of natural, professional, and community supports, as well as assisted technology while performing their role as co-researchers. **Conclusion:** Inclusive research is a challenging evolving process and it requires ongoing support and feedback to monitor the process and the outcomes to guarantee that all the participants perform different roles involved while meeting the goals of the research.

**Keywords:** adults, intellectual disabilities, inclusive research, self-perceptions

## Background

The movement towards the recognition of human rights within the broader disability field culminated in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006). The UNCRPD expresses the key tenets of the disability human rights movement in its general principles, which emphasize autonomy, choice, independence, equality and participation (McCausland, McCallion, Brennan, & McCarron, 2018).

As stated by Salmon, Barry, and Hutchins (2018), the UNCRPD sets the framework for conducting inclusive research in the field of disability studies. Specifically, Article 4 sets the obligation to promote research and develop best practices of universally designed goods, services, equipment and facilities. It also states that, in the development and implementation of legislation and policies, and in other decision-making processes, people with disabilities should be consulted and involved. Other relevant sections are: Article 5 which prohibits discrimination; Article 8 which establishes the need to promote awareness of the capabilities and contributions of persons with disabilities, as well as on their rights. Further, Article 9 underscores the need to guarantee access to the physical environment, transportation, information and communications, and to other facilities and services provided to the public. Likewise, Article 31 states that statistics and data collection must be accessible to persons with disabilities. In accordance to this international law and mandate, advances in national legislations worldwide are increasingly recognizing the status of people with disabilities as subjects of law. This is the case with Chile, where this study has been carried out. Thus, since 2010, Chilean public policies on disability are providing responses to the demands of the population with intellectual disabilities concerning their human rights [Author, 2012a, 2012b].

These new demands require methodological approaches that allow putting individuals with disabilities at the center of the research. It is increasingly important to know what they think, feel, perceive, value, and what they demand. To answer these questions, qualitative approaches, which are concerned with bringing knowledge of the unknown into the known, are preferable to quantitative ones (Morse & Field 1995). This helps explain why qualitative methods are playing an increasing role in bringing out the unknown about people who have intellectual disabilities (Beail & Williams, 2014). Qualitative research methods include in-depth interviews, interviews with design approaches called cultural probes (Mawson et al., 2014; Nasr et al., 2016), and narrative analysis, among others. It also requires qualitative data analysis such as content analysis, or computer-assisted analysis (Beail & Williams, 2014; Strauss & Corbin, 2008). As the reader will notice along these pages, we have utilized these methodologies, not only to conduct the research on cognitive accessibility, but also in the inquiry about the experience of co-researchers.

These approaches are aligned with what is called inclusive research where people with intellectual disabilities are engaged not only as research subjects, but also as research collaborators (Shogren & Turnbull, 2014; Walmsley, Strnadová & Johnson, 2018).

Additional support tools that have been used for analysis are visual representations (Kramer, Garcia-Iriarte, & Hammels, 2011), and photovoice (Cluley, 2017). Inclusive research is a way of extending self-advocacy and activism in academia, by supporting people with intellectual disability to engage in academic activities, including teaching and researching (Callus, 2019). In this regard Johnson (2009) adds that inclusive research is based on values and ideas which strongly emphasize the importance of research arising from the expressed interests and issues of people with intellectual disabilities. Participating in a research process also provides the opportunity to acquire conceptual, procedural, and attitudinal competences required to carry out an investigation, and participants need to feel sufficiently confident and skilled to be able

to participate (Burke et al., 2003). This allows generating individual and social changes with high impact in their lives (Salmon, Barry, & Hutchins, 2018; Walmsley et al., 2018).

Inclusive research encompasses a range of research approaches that have been called participatory, action or emancipatory (Johnson, 2009; Ollerton & Horsfall, 2013; Salmon, Barry, & Hutchins, 2018). Strictly speaking, in emancipatory research the control over most, if not all, aspects of the research remain within the remit of representative organizations of people with disabilities and the people with disabilities, and it is pursued in their interest (Redmond, 2005; Walmsley, 2004). Meanwhile, inclusive or participatory research approaches are situated on a spectrum ranging from an advisory approach, through approaches where people with intellectual disabilities initiate, lead, and implement their own research (Dorozenko, Bishop, & Roberts, 2016). Additional characteristics of these approaches are: the research should further the interests of disabled people, the process should be collaborative, people with intellectual disabilities should be able to exert some control over the process and outcomes, and the research question, process and reports must be accessible to people with intellectual disabilities (Haigh et al., 2013; Shogren & Turnbull, 2014; Walmsley & Johnson, 2003).

Increasingly, international research highlights that the disability research process must be considered from a rights perspective. This implies rethinking the role of people with intellectual disabilities in the research processes that concern them (Johnson, Minogue & Hopkins, 2014; O'Brien, McConkey & García-Iriarte, 2014; Pallisera, et al., 2017). In fact, specialized literature is progressively adopting a more inclusive research approach (Beighton et al., 2017; Dorozenko, Bishop, & Roberts, 2016; Frankena et al., 2019; Haigh et al., 2013; Iriarte, et al., 2014; Johnson, 2009; Johnson et al., 2014; Salmon et al., 2018; Walmsley & Johnson, 2003; Walmsley, Strnadová & Johnson, 2018), and co-researchers even appear as coauthors of the articles (Burke et al., 2003; Flood, et al., 2013). There are several examples,

especially in English speaking countries, that illustrate their roles as advisors (see for example: Keyes & Brandon, 2012; Kidney & McDonald, 2014) when participating in research. Other studies have been implemented entirely by people with disabilities where they become leaders and managers of social change (Fullana, et al., 2016; Haigh et al., 2013; Michell, 2012; Pallisera et al., 2017).

People with disabilities themselves acknowledge that being involved in this type of research has helped them to learn new skills, defend their rights, express themselves freely about matters that are important to them, provided participation in a socially valued activity, improved their self-esteem, their relationship with the environment, optimized their time, consolidated their self-efficacy, and metacognitive processes (Embregts, et al., 2018; García-Iriarte, O'Brien & Chadwick, 2014; Fullana et al., 2016; Kidney & McDonald, 2014; Nind, 2016; Petri, et al., 2018; Salmon, Barry, & Hutchins, 2018; Strnadová, Cumming, Knox & Parmenter, 2014; White & Morgan, 2012) .

Carrying out research requires paying attention to different processes: the problem statement, research hypothesis, planning, information gathering, and data analysis among others (Pallisera et al. al., 2017). Supporting these processes in the framework of inclusive research involves facilitating the participation of people with disabilities on each of those steps (Tuffrey-Wijne, et al., 2009; Tyrer et al., 2017). Yet, international literature barely offers suggestions on how to orient these processes (Abell et al., 2007; Strnadová et al., 2014). Most papers focus on sharing practicalities of inclusive research in order to support others in conducting inclusive research, but the study of roles and relationships within inclusive research has received little attention and has focused mainly on short-term projects (Frankena et al., 2019). Most of these initiatives do not clarify the responsibilities of researchers with intellectual disabilities during the development of these processes (Bigby et al., 2014). Just a few studies, such as those carried out by Nind (2016) and Petri et al. (2018), refer to the roles

assumed by people with disabilities who are called experts by experience. However, it is necessary to continue advancing in the definition of the roles of researchers with disabilities, as it is key for the success of this type of research (Pallisera et al., 2017). Inclusive research teams need to write more about how they work together on projects, to give others' ideas about 'how to do' good research that matters to people with learning disabilities (Salmon, Barry, & Hutchins, 2018). Similarly, Dorozenko et al., (2016) claim that few published papers have offered reflections on the process of doing participatory research or provided descriptions of the roles of people with intellectual disabilities in the research process (Dorozenko et al., 2016).

Additionally, clarifying the supports that people with disabilities receive to participate actively in research processes is another issue that needs to be addressed (Embregts et al., 2018). Describing the types of support will help define the tasks during the process, respect the roles and ensure that people with intellectual disabilities are really doing research (Cluley, 2017).

Starting from these premises, this current research focuses on describing the experience of a group of Chilean adults with intellectual disabilities who participated as co-researchers, in an inclusive research project aimed at assessing the cognitive accessibility of public spaces and transportation in a Chilean city. The focus of this paper is not to describe the findings regarding cognitive accessibility, but to illustrate the process, roles, difficulties, and advantages of performing an inclusive research. This research will allow identifying roles associated with their work as researchers and describe potential supports that facilitate the development of inclusive research. The specific aims are to: (1) report the experience of involving adults with intellectual disabilities in an inclusive research process, and their improvements in terms of developed competencies; (2) identify their perceived roles as co-researchers, and (3) describe the perceived barriers and facilitators during the research



process, as well as supports provided during this process. Thus, this paper synthesizes the experiences, reflections, and tasks performed by the co-researchers who participated for 14 months in a research on cognitive accessibility led by an interdisciplinary group of researchers, mostly from [blinded for review].

## Method

### *Participants*

To conduct the study on assessment of cognitive accessibility of public spaces and transportation in a Chilean city, a purposive sampling of co-researchers was selected (Holloway & Wheeler, 2010). The selection of participants was made through organizations and their users with intellectual disabilities who had previously participated in a project on self-determination with independent living, so we were in contact and knew about their commitment and inclusive vision of the services they provide. After the approval of the project by the ethical commission of [university blinded for review] (Chile), the structure of the teamwork was established. The inclusion criteria for the co-researchers were: be over 18 years old, have communication skills, have been actively involved in institutions supporting independent living and have a diagnosis of mild to moderate intellectual disability. Finally, the co-researchers included consisted of 11 adults (six men and five women) with intellectual disabilities whose ages ranged between 23 and 55 years ( $M = 32.73$ ,  $SD = 11.02$ ). Six researchers (two special educators, two designers, one psychologist, one sociologist) from the University of [blinded for review] participated in the project as team members as well. All the co-researchers lived with their families and three worked in mainstream employment.

### *Procedure followed to involve co-researchers in the study on cognitive accessibility*

For the selection of co-researchers, the main disability care organizations of [blinded for review] were contacted and information on the objectives of the study and the inclusion criteria of the potential co-researchers were provided. An initial meeting was set in

[university blinded for review] with potential co-researchers and the focus and theme of the research was explained, as well as the planned schedule and required commitments timewise, and so on. Once co-researchers voluntarily signed the informed consent, the research process started, and weekly meetings were set to carry out the research. The process involved 14 months of work, with weekly sessions of three hours length, which required not only interest and willingness to participate, but also time availability for the research team.

The procedure of involving co-researchers evolved as the project developed (see Table 1).

The process can be grouped into three phases or tasks: training, designing, and executing. In the training or induction stage, participants acquired skills to address the initial stages of a research process, such as: (1) selecting and defining a research problem, (2) formulating hypotheses, objectives and research questions, and (3) selecting the research design and related procedures, activities, and tools. Co-researchers not only received training but also performed some activities, such as participating in the item and question development and in the preliminary validation of the tool. They also participated in the planning of data collection, by selecting public spaces and areas to be evaluated, and in the development of the spreadsheet and the scoring system.

-----Insert Table 1 about here-----

An example of the items to be evaluated for cognitive accessibility in the metro line can be seen in Table 2. The two team designers lead the process and explained to the rest of the team the domains to be included in the assessment by the co-researchers. The co-researchers offered their viewpoints on the items to be included for each domain (e.g. font size of the posters, message understandability) and the team helped them name the different items.

-----Insert Table 2 about here-----

Finally, during the data collection, the co-researchers tested the cognitive accessibility instrument they helped develop. The tool was utilized to assess public spaces, and they also

interviewed people with intellectual disabilities to obtain information on their evaluation of the cognitive accessibility of those public spaces. They also interviewed people without intellectual disabilities and certain personal conditions (e.g. elderly) to determine if the information was cognitively accessible enough for them. On average, each co-researcher interviewed three individuals to assess the cognitive accessibility of the metro line.

The co-researchers also participated in the data management and analysis, as well as in the dissemination of the findings.

On the tasks and skills summarized in Table 1, it is important to note that although co-researchers are experts by experience in issues related to what is understandable (i.e. cognitive accessible) to them, they needed, as a first task, to learn about the topic in order to share a common language with the rest of the team members, as well as to being able to identify issues or areas to assess in the topic of interest. The second task, formulating the research questions (Table 1) involved helping them translate accessibility concerns into formal research questions to guarantee that they were precise, specific, and measurable enough. The third task required understanding the association between hypotheses and techniques to contrast them. Among the existing assessment techniques, co-researchers decided which techniques would be more useful for the research purposes. Supports to ensure the adequate use of those tools were proposed and agreed in task 4. Concerning the informed consent, similar to Dorozenko et al., (2016), an ongoing process throughout the duration of the research project was adopted in two senses; on the one hand with respect to the co-researchers and on the other hand, with respect to the people to be interviewed in the field work. In task 5, the information sheet and consent forms created for the project utilized simple language, bullet points, pictures, and the repetition of information, in order to guarantee comprehensibility and readability of potential interviewees. Task 6 required co-researchers to select the public spaces to be evaluated. The selection was based on their

preferences and relevance to their daily living. Task 7 was challenging, as data-gathering is a complex skill and it required guided visits, role-playing, modeling, and the use of cultural probes. Tasks 8 and 9 dealt with data management and data analysis. Strategies such as paper-and-pencil, and photovoice followed by discussion and identification of main themes and codes were utilized.

#### *Procedure to assess the experience as co-researchers*

In addition to participating in the research process, co-researchers were individually interviewed as experts by experience, to gather information on what it meant to them to be involved in an inclusive research and what did they learned. A guide for the semi-structured interview, following the recommendations of Flick (2007) and Sandín (2003), was developed. Every participant was interviewed and each interview lasted one and a half hours, on average. Content analysis of the responses was then employed. This, again, required informed consent as their comments were registered, transcribed, and coded. Three categories were established to structure the interview: (1) research experiences (i.e. What has it meant for you to be a researcher in this project?, What have you learned in your work as a researcher?), (2) roles assumed during the research process (i.e. What tasks have you done in your work as a researcher?, What have you had to do to be a researcher?), and (3) identified barriers and supports (i.e. Did you find any barrier when developing your role as co-researcher?, Did you find any support when developing your role as co-researcher?). The co-researchers were consulted to verify that questions were understandable to them.

The answers were transcribed, and an analysis of thematic content was carried out (Sandín, 2003) with the ATLAS.ti program. The analysis of transcriptions focused on the competencies co-researchers developed during their involvement in the research, their experiences and roles as co-researchers in the inclusive research process, according to pre-defined conceptual categories proposed by Sipe (2004) (see Table 3), as well as barriers and

facilitators they found when developing their role as co-researchers. It is important to mention that co-researchers were not involved in the coding of this information, although they received feedback on the findings of this process. Table 3 offers textual fragments for the different codes and participants.

## Results

### *1. Competencies developed during their involvement as co-researchers*

The information gathered during the individual interviews allowed identifying their awareness regarding the development of conceptual (e.g. what is cognitive accessibility, what does it mean to evaluate), procedural (e.g. how to conduct an interview, how to code the interviews), and attitudinal competences (e.g. being a reliable researcher, being empathic). In fact, in the transcripts, conceptual competences related to what it means to conduct research are highlighted by participants: "To investigate is to observe what one can solve" (CR1). "To be a researcher is to look for information by observing and investigating objects" (CR 4). "To investigate means to find out something that I do not know" (CR 2). The interpretation they make about the purpose of the research processes is worth noting. In general terms, attitudinal competences are stressed by the social role they pose on the research: "To investigate is to listen to people and their things" (CR 6). "Research is about finding out, supporting and helping" (CR 5). "If the researcher does not look at what the person needs, the investigation will be a failure" (CR 7).

-----Insert Table 3 about here-----

Also, the co-researchers' discourses show that they distinguish between the different phases of a research process, and that they recognize the need to acquire procedural competences in order to best meet the challenges posed by the different stages: "It is not the same to be evaluating as analyzing "(CR 3). "To investigate first you have to find out concepts that you do not understand" (CR 5). "If you do not learn to go out in the field, you do not know how to

investigate" (CR 2). The transcripts show how, for the co-researchers, investigating involves sequential and task-oriented actions with the ultimate goal of gathering information and reporting it to the research team: "If you ask me, I will know what to talk, I can tell what I know , what I have learned about the subject "(CR 9). In the same way, their comments stress some motivations to investigate. The interviewees understand this dimension as a professional occupation that acquires a relevant place in their lives: "It motivates me to be a co-researcher to help other people to understand this, take these issues seriously" (CR 11). "I like to talk, to give ideas, I like to share with many people, go out to the field to investigate, I think it is a great contribution" (CR 10). "It is important to form teams of researchers like the one that is being formed" (CR 8).

## *2. Experiences and roles of the co-researchers in the inclusive research process*

The analysis of the data provided by the interviews provides a picture of perceived roles played as co-researchers (CR): Apprentices, evaluators, analysts, collaborators, and experts by experience, as we have summarized in Table 3. Regarding the role as apprentices, the co-researchers reflect on the training or induction on the different phases that make up the research processes and the main concepts to work on: "To me that term cost me a bit (referring to evaluating) and what I learned more "(CR 7). "Now I understand what cognitive accessibility is and its importance" (CR 3). At the same time, evidence related to the learning acquired in the research processes is appreciated: "You learn from what you are evaluating, learn from what you are looking at and what you are doing" (CR 5). Likewise, they identify not only conceptual but also attitudinal learning: "I have learned to share with colleagues and researchers" (CR 6).

With respect to the role of evaluators, they relate some activities carried out: "I look, I observe, I write the things that are missing and the things that are not missing, things they are fine and the things that are not right "(CR 2). "I'm taking notes on a sheet and the things that

are missing I'm writing them and then I'll talk about them here" (CR 6). "I tried to ask the service staff if they could change that (referring to the size of the letter of a poster) to make it more accessible" (CR 1).

Some comments illustrate the role of analysts: "Before speaking I have to think. For example, if I see a poster I have to think if what is on the poster makes me understand it "(CR 5).

"When I saw the access path (in the museum) I realized that it has a ramp and is in a good environment. This is important for people with disabilities and even for those who do not have them "(CR 8). In addition, the co-researchers also made reflective analysis about the process: "After observing all this, I have become aware that other people can also be researchers" (CR 2).

Other comments reflect the role of collaborators: "Review the questions, to say if one understands the pattern, the colors, the forms, to test them in the field... In that I have contributed a lot "(CR 9). In the same way, they conceive collaborative work as an instance that promotes learning about the needs of other people: "By working in this way one learns from the reality of other people, listening to what others say" (CR 2). "Working in this way helps to meet new people, see new spaces and realities that perhaps one has never lived" (CR 11).

On the other hand, regarding their role of experts by experience, they express that: "We must explain to all the people how we have taken steps from here to work on accessibility "(CR 10). Likewise, they understand that the research benefits the whole society: "The issue of accessibility is not only seen by me but by other people as well" (CR 5). As they acknowledge: "I did not study five years in a university, but the experience it guides you, it gives you the power to train others "(CR 1). "You (researchers) taught us (co-researchers) and now we teach you" (CR 6).

Note, the most mentioned role assumed by co-researchers is the expert by experience, followed by the apprentice. The least mentioned role is the analyst. The majority of the participants referred to four roles undertaken during their experience as co-researchers. Some differences can be identified, for example, some participants (e.g. CR3, CR7) only mentioned two roles, which suggest that their involvement was not as comprehensive as for some of their colleagues.

### *3. Barriers and facilitators for the development of the role of co-researchers*

As summarized in Table 4, the co-researchers refer to the attitudes of people as one of the main barriers for their work as researchers to be recognized: "people think that people with intellectual disabilities do not have the conditions to be researchers" (CR 9). "Society does not value all the work we do because we have a disability" (CR 1). "When you're doing field work, some of you respond ugly" (CR 8). "People are not empathetic with us" (CR 2).

Another barrier has to do with the difficulties related to lack of supports in natural environments to perform a task: "When the professionals have given me an instruction, sometimes it is hard for me to understand what it is that they are asking" (CR 4). "The information we receive (referring to the instructions of a task) is sometimes unclear" (CR 1). "When professionals give us information, they get entangled" (CR 5). The lack of accessibility is also reflected in the visual information offered: "I have a hard time understanding the signs (of the museum)" (CR 10). "It's hard for me to look at the subway signs. Sometimes colors are good and there are others that stay off "(CR 9).

In the same way, the co-researchers emphasize the few opportunities to disseminate the findings of the research: "There is nowhere to tell what we are investigating here" (CR 4). "There are very few places where they want to hear what we have to say about accessibility" (CR 1). They also refer to the lack of confidence and training to assume certain tasks, or problems to interact correctly with others (users or service officials who have been



interviewed) throughout the process: "Sometimes I feel that I am not able" (CR 7). "It has been difficult to learn to interview others" (CR 6).

With respect to the elements that facilitate the recognition of their role as researchers, the formal support received by the different professionals (academics) is stressed: "I really liked working with R. (engineer) because he interviewed a person on the subway, I paid attention and then I conducted an interview and I did it very well" (CR 4). "I needed help for something and N. (sociologist) helped me to get my bearings" (CR 7). It should be noted that collaborative work is one of the strengths for achieving tasks associated with the investigative role: "I like that in the team everyone has their opinions because that supposes a contribution as a researcher" (CR 8). "We all help each other; we ask ourselves to solve problems" (CR 11).

Natural supports also stand out as a facilitator for the consolidation of research skills. The personal skills derived from participation in this process are also identified: "Since I am here (refers to being co-researcher) I feel more empowered" (CR 9). "Investigating I have learned to do work for myself" (CR 8). Peer support also stands out as being an aspect that facilitates the consolidation of the members with intellectual disabilities as co-researcher: "When I have had problems during the process (research) I have relied on my colleagues" (CR 4). "One learns to be a researcher with others" (CR 2). "The rest of the group (of co-researchers) is an important support to be able to do the tasks" (CR 1). "The research is done as a team" (M5). In the same way, family and friends contribute significantly to facilitate their role as researchers: "In my house they encourage me to come" (CR 7). "My friends tell me I do something important here" (CR 10).

-----Insert Table 4 about here-----

Likewise, it is important to highlight the implication of the community environment for the achievement of the different tasks of the research process: "The university has opened its

doors for us" (CR 1). "It was good that the people who use the metro and those who work there helped us" (CR 9). Finally, the co-researcher rely on the support of technology as another element that has helped to facilitate the performance of their role as co-researchers: "Everything was designed for us: from the images to what had to be read to evaluate" (CR 3). "Being able to take pictures to assess accessibility has been very good because I find it difficult to write" (CR 2).

## Discussion

First, this study shows that people with intellectual disabilities can be co-researchers, which contributes to increase the evidences in this regard (Flood, Bennett, Melsome, & Northway, 2013; Frankena et al., 2019; Kramer-Roy, 2015; Redmond, 2005). Being a co-researcher is even more important when the focus of the research is a topic closely related to them, such as the cognitive accessibility of public spaces and services.

This study also shows that being involved in the different phases of a research requires time, effort, and training. Being able to identify research questions, specify hypotheses, select tools to evaluate a topic, analyze data and summarize and disseminate the findings are quite sophisticated skills, even for postgraduate students. So, carrying out an inclusive research requires a significant amount of time, as the co-researchers should acquire both generic methodological skills and specific training in the topic under study. The planning process has also been long and difficult because, as Walmsley (2004) states, there is no one right way to approach inclusive research, and adjustments are needed according to the topic, the methodology and the skills of those involved. We also found that not all the participants have undertaken the same type and number of roles. As carrying out a research means assuming diverse roles such as apprentice, evaluator, analyst, collaborator, and even expert by experience, we sustain that we should provide co-researchers with the opportunities and supports to exercise each of these roles while obtaining their feedback to verify, as in this

study, how well these opportunities and supports are provided. We acknowledge that there are different positions regarding what it means to be involved in inclusive research, what is the added value of this involvement, and to what extent “co-researchers with intellectual disabilities should become “real researchers”, able to understand the literature, to analyze the data and select appropriate methodologies” (Walmsley, Strnadová, & Johnson, 2018, p. 2). For example, Walmsley et al., (2018) argue that, although some state that the main added value of inclusive research is to equip people with intellectual disabilities with academic research skills, for them the main added value of inclusive research is that people with intellectual disabilities bring something unique to the research process and to the quality of the research (p.3). In this study we emphasize the relevance of both factors.

First, we believe that equipping people with intellectual disabilities with research skills is a key outcome that should be evaluated. Acquiring those skills will allow them, like any other apprentice researcher, to develop critical thinking skills, and the capability to ask and answer questions of increasing complexity. With this study we have taken a first step, starting with a specific and more objective topic, namely cognitive accessibility. Subsequent studies could address more controversial issues such as legalization of marijuana, abortion, same-sex marriage, or euthanasia, to give just a few examples. These topics are being debated among the general population and they can offer their perspective and their particular experience. Doing co-research only on disability issues, because they share this condition, is limiting, prejudiced and far from rights and citizenship perspectives.

A second added value (Walmsley et al., 2018) relates to the quality of the process and the results. The involvement of people with intellectual disabilities in the whole research process forces the research team to think and design the entire process to ensure that it is understood by very diverse participants. By doing so, the process is improved, as it requires greater reflection, better planning, more specification of the steps and tasks to be undertaken, and

less restrictive inclusion criteria of participants, derived from having fewer restrictions associated to the ability to understand, read, write, communicate, and the like. All this increases the generalizability of the results, that is, the external validity of the research itself. We agree with Walmsley, et al., (2018) who affirm that inclusive research must be characterized as contributing to social change, be drawn on the experience of people with intellectual disabilities to inform the process and results, highlight the contribution that these people can make, help promote changes on issues that concern them, and research alongside those whose topics of interest are being explored. In fact, this study tries to illustrate the process followed to guarantee these aspects. And, in addition, we defend that an inclusive research must offer evidence of the improvement of co-researchers with intellectual disabilities in the areas and skills required to carry out research.

Inclusive research is a matter of rights, and it is also the right thing to do, when investigating on issues that concern this population. As experts by experience in issues that concern them, researchers with intellectual disabilities are in the best position to explain what they think, how they feel, what they need, and the like. They are in the optimal position to bring knowledge of the unknown into the known (Beail & Williams, 2014), which in this specific study on cognitive accessibility was: what is it like for a person to visit a museum or to travel by metro while being unable to understand signs, posters, and signals. From a rights perspective, it is our responsibility to help them identify unmet needs, and to transform those needs into expressed demands for better services [Author, 2012a] or, as in this case, more cognitive accessibility in public transportation and services. The best approach, and the most aligned with the mandate of the UNCRPD, is to involve them in the research process from the beginning, and to monitor the process to be sure that they are not left behind in any of the steps and tasks.

Qualitative approaches are more suitable for participatory research (Beail & Williams, 2014), but quantitative approaches should be also supported and facilitated, as many scientific journals privilege the adoption of quantitative approaches, which increases the possibilities of disseminating the results and demonstrating the advantages of having co-researchers.

When people with intellectual disabilities participate as co-researchers in topics that concerns them, they not only learn how to conduct research, but they also benefit from the findings of the research itself. They also learn that the outcomes of a research may benefit the whole society as well (Beighton et al., 2017, Pallisera et al., 2017). This helps them become agents of social change (Pallisera et al., 2017, Tyrer et al., 2017), which is an excellent path for their empowerment. In this regard, the co-researchers of the current study expressed their satisfaction for respecting human rights that have been historically neglected (Flood, et al., 2013). This exemplifies the transformative power of participatory and inclusive research (Genov, 2002; Pallisera et al., 2017).

The co-researchers of this study, in line with Beighton et al. (2017) and Salmon, Barry, and Hutchins (2018), consider that formal and natural supports constitute one of the main facilitators of inclusive research processes. Specifically, and coinciding with other studies (Fullana et al., 2016; Salmon, Barry, & Hutchins, 2018), the collaboration of the peer group and the guidance of the team of academics is an important help in the development of their role as co-researchers. In contrast, contextual barriers have been identified and relate to the lack of credibility that society has with respect to their abilities to carry out research tasks. Therefore, the focus should be on the socio-political context and be oriented towards the struggle for rights and the participation of people with intellectual disabilities in every life domain (Nind & Vinha, 2014; O'Brien et al., 2014).

Among the limitations of the study, due to the characteristics of the study and its approach, is that the information depends of the observation and communication capabilities of the

informants, as well as the capabilities of the interviewers. These limitations suggest that the data obtained should be completed and contrasted with other evaluation techniques (Berg, 2001). Second, personal variables, such as level of severity of disability, difficulties in adaptive behavior and the intensity of support, have not been controlled in this study. Third, the entire process reflects almost two-years work, so its presentation is necessarily incomplete.

However, this study also has important strengths. First, it provides a detailed report on the process of involving adults with intellectual disabilities in an inclusive research and it can be used as a preliminary blueprint for future efforts. It also shows the benefits that this type of research has for people with intellectual disabilities in terms of developing research competencies, and for the quality of the research itself. It also helps to clarify the roles that people with disabilities in these processes may play and to identify barriers to remove and supports to carry out successful inclusive research. Finally, this study demonstrates that inclusive research is a challenging process and it requires of ongoing support and feedback to monitor the process and the outcomes to guarantee that the goals of both the research and the participatory approach are achieved.

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Table 1.

Task and skills for the research process, activities performed by co-researchers in the cognitive accessibility study, and available supports

<b>Task (and skills)</b>	<b>Activities performed</b>	<b>Supports</b>
1. Selecting and defining a research problem (Training)	<ul style="list-style-type: none"> <li>- Readings on accessibility</li> <li>- Discussion on universal accessibility</li> <li>- Receiving information on definitions of cognitive accessibility</li> <li>- Identifying types of cognitive accessibility</li> </ul>	<ul style="list-style-type: none"> <li>- Easy-reading material</li> <li>- Audio-visual material</li> <li>- Support from specialists on special education and design</li> </ul>
2. Formulating the research question (Training)	<ul style="list-style-type: none"> <li>- Identifying research topics on cognitive accessibility</li> <li>- Training in formulating hypotheses and research questions</li> <li>- Co-defining hypotheses and research questions</li> </ul>	<ul style="list-style-type: none"> <li>- Easy-reading material</li> <li>- Audio-visual material</li> <li>- Support from experts on research</li> </ul>
3. Choice and development of research method (Training)	<ul style="list-style-type: none"> <li>- Training on paradigms and scientific research techniques</li> <li>- Identifying the steps of a scientific research</li> <li>- Defining the steps to perform in a scientific research process</li> <li>- Selecting tools to assess cognitive accessibility</li> </ul>	<ul style="list-style-type: none"> <li>- Easy-reading material</li> <li>- Audio-visual material</li> <li>- Support from experts on research</li> </ul>
4. Writing the protocol (Training and Designing)	<ul style="list-style-type: none"> <li>- Review of steps for the design of assessment tools on cognitive accessibility (interviews and cultural probes)</li> <li>- Identification of assessment domains and indicators</li> <li>- Items and questions development</li> <li>- Preliminary validation of items and questions on cognitive accessibility</li> </ul>	<ul style="list-style-type: none"> <li>- Easy-reading material</li> <li>- Audio-visual material</li> <li>- Support from experts on special education and research</li> </ul>
5. Ethics committee	<ul style="list-style-type: none"> <li>- Review of the informed</li> </ul>	<ul style="list-style-type: none"> <li>- Easy-reading</li> </ul>

application (Training)	<ul style="list-style-type: none"> <li>- consent protocol</li> <li>- Information on the ethical implications of a research</li> </ul>	<ul style="list-style-type: none"> <li>- material</li> <li>- Audio-visual material</li> <li>- Support from the Ethics Committee of the University</li> </ul>
6. Planning of data collection (Designing)	<ul style="list-style-type: none"> <li>- Selection of public spaces to be evaluated</li> <li>- Developing a map of the places to be evaluated</li> <li>- Development of the interview guide used in the selected public spaces</li> </ul>	<ul style="list-style-type: none"> <li>- Easy-reading material</li> <li>- Audio-visual material</li> <li>- Support from experts on special education and research</li> </ul>
7. Pilot test of data gathering (Executing)	<ul style="list-style-type: none"> <li>- Visit to public spaces to be evaluated</li> <li>- Training (role-playing, modeling) on how to conduct the interviews</li> <li>- Interviewing users of public spaces under evaluation</li> <li>- Utilization of cultural probes to evaluate public spaces</li> </ul>	<ul style="list-style-type: none"> <li>- Easy-reading material</li> <li>- Assisted Technology</li> <li>- Support from specialists on research, special education and design</li> </ul>
8. Data management (Executing)	<ul style="list-style-type: none"> <li>- Data gathering in digital and paper-and-pencil format</li> <li>- Use of photovoice methodology for preliminary analysis of the data</li> </ul>	<ul style="list-style-type: none"> <li>- Easy-reading material</li> <li>- Assisted Technology</li> <li>- Support from specialists on research</li> </ul>
9. Data analysis (Executing)	<ul style="list-style-type: none"> <li>- Categorization of gathered data</li> <li>- Discussion of findings and conclusions of the evaluation process.</li> </ul>	<ul style="list-style-type: none"> <li>- Visual supports (photos, pictograms)</li> <li>- Support from specialists on research</li> </ul>
10. Prepare report and publications (Executing)	<ul style="list-style-type: none"> <li>- Participation in group interviews to evaluate the research process and main findings</li> <li>- Presentation of the research experience and findings in scientific forums</li> </ul>	<ul style="list-style-type: none"> <li>- Easy-reading material</li> <li>- Support from experts on special education and research</li> </ul>



Table 2.

Cognitive accessibility of the metro system. Spreadsheet.

**1. Visual support**

a. Is there a Metro line poster? Yes/No

If affirmative, please score each item:

1=not understandable; 2=requires help; 3=difficult; 4=Understandable; 5=Perfect

- Font size
- Poster size
- Poster colors
- Font type
- Text and image
- Clarity of the information
- Cleaning
- Brightness
- Poster location

b.- Is there a map of the place? Yes/No

If affirmative, please score each item:

1=not understandable; 2=requires help; 3=difficult; 4=Understandable; 5=Perfect

- Font size
- Poster size
- Poster colors
- Font type
- Text and image
- Clarity of the information
- Cleaning
- Brightness
- Map location

c.- Is there a panel? Yes/No

If affirmative, please score each item:

1=not understandable; 2=requires help; 3=difficult; 4=Understandable; 5=Perfect

- Font size
- Poster size
- Poster colors
- Font type
- Text and image
- Clarity of the information
- Cleaning
- Brightness
- Panel location

d.- Are there signs? Yes/No

If affirmative, please score each item:

1=not understandable; 2=requires help; 3=difficult; 4=Understandable; 5=Perfect

- Font size
- Poster size
- Poster colors
- Font type
- Text and image
- Clarity of the information
- Cleaning
- Brightness

- Signs location

d.- Are there elements to help locate him/herself? Yes/No

If affirmative, please score each item:

1=not understandable; 2=requires help; 3=difficult; 4=Understandable; 5=Perfect

- Font size
- Poster size
- Poster colors
- Font type
- Text and image
- Clarity of the information
- Cleaning
- Brightness
- Elements location

## **2. Support personnel**

a.- Is there support personnel? Yes/No

If affirmative, please score each item:

1=not understandable; 2=requires help; 3=difficult; 4=Understandable; 5=Perfect

- Are they well identified?
- Are they located in a visible place?
- Is it easy to access them?
- Is the information they deliver understood?
- The information they deliver is clear
- Is the personnel kind?
- Is the personnel respectful?

## **3. Evaluation of the public space**

Please rate:

1=Not at all; 2=poor; 3=somewhat; 4=good; 5=Great

The place is nice

- I feel comfortable in the place
- The place is clean
- The place has good lighting
- The sound of the place is adequate
- The space is safe
- The space is organized

Table 3.

Evaluation of the experience as co-researcher

Participant	Apprentice	Evaluator	Analyst	Collaborator	Expert by experience
CR1		"I tried to ask the service staff if they could change that (referring to the size of the letter of a poster) to make it more accessible"	"What I have to think when I see a poster is what is in that poster and if it is understood"	"In Chile they don't know what accessibility means; a lot is missing to have accessibility, and we can support this to happen"	"I did not study five years in a university, but the experience guides you, it gives you the power to train others "
CR2	"I have learned that there are many different things to investigate, that is, it is not the same evaluating as investigating"	I look, I observe, I write the things that are missing and the things that are not missing, things that are fine and the things that are not right "	"After observing all this, I have become aware that other people can also be researchers"	"By working in this way one learns from the reality of other people, listening to what others say"	
CR3	"Now I understand what cognitive accessibility is and its importance"			"The positive thing is that we are a kind of teacher who helps, meets new people, new spaces, etc."	
CR4	"I have learned that when I do something I should always think about how can I improve it the next time"	"I research and write the things that I think are right and the things that I think are wrong"		"I explain to people what we do here and help them understand what accessibility is"	"This is a job, an enriching, friendly and motivating experience that has an impact on everyone's life"
CR5		"I liked being an evaluator on the subway. I have realized that it is not so accessible and it is necessary to improve a lot"	"Before speaking I have to think. For example, if I see a poster I have to think if what is on the poster makes me understand it "		"The issue of accessibility is not only seen by me but by other people as well"
CR6	"I have learned to share with colleagues and	"I'm taking notes on a sheet and the		I am a researcher, because I have	You (researchers) taught us (co-researchers) and

	researchers"	things that are missing I'm writing them and then I'll talk about them here"		searched ... I like the challenge, to search and find.	now we teach you"
CR7	"To me that term cost me a bit (referring to evaluating) and what I learned more "				"I would like to explain to other people or to any of us, from the co-researchers perspective, what cognitive accessibility is"
CR8	"That cost me a bit (he refers to evaluating) and here I learned about it more"		"When I saw the access path (in the museum) I realized that it has a ramp and is in a good environment. This is important for people with disabilities and even for those who do not have them "		"I felt like a researcher because I knew how to conduct interviews and many other things"
CR9	"If they ask me, I will know what to say, I can tell what I know, what I have learned on the subject"	"I also evaluate my performance as researcher"		Review the questions, to say if one understands the pattern, the colors, the forms, to test them in the field... In that I have contributed a lot "	"I feel like a researcher ... I feel proud of the team"
CR10		"I have realized that there are things in the subway that are not well understood. If I had arrows or images they would be better understood"	"I like to talk, give ideas, I like to share them with many people, go out to the field to investigate"		"We must explain to all the people how we have taken steps from here to work on accessibility "
CR11	"I have learned many things; I have learned to be in a group		"It is important to collect the maximum amount of	"Working in this way helps to meet new people, see new	"I can explain what cognitive accessibility is, because people

	with my colleagues and to have respect"		information and tell people all the information you got"	spaces and realities that perhaps one has never lived"	don't know (...) so you have the ability to explain it more fully, you have time to talk and explain what it is, I can give a talk on cognitive accessibility, a talk for that people understand what it is"
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Table 4.

Barriers and facilitators of inclusive research identified by the co-researchers

<b>Barriers</b>	
Contextual	<p>Social attitudes towards disability (little credibility)</p> <p>Lack of supports in spaces, resources and services</p> <p>Few instances to disseminate the results to the community</p>
Personal	<p>Lack of confidence to take on some tasks during the process</p> <p>Lack of training on research topics and cognitive accessibility</p> <p>Problems with interacting properly with service users</p>
<b>Facilitators</b>	
Personal support	<p>Peer group (other co-researchers) and teamwork</p> <p>Personal competences (empowerment...) and intrinsic motivation</p> <p>Family environment and close friendships</p>
Professional support	<p>Team of academic specialists in research and disability</p> <p>Specialists in cognitive accessibility and special education</p> <p>Specialists in industrial design and computing</p>
Community support	<p>Inputs provided by the university (infrastructure, materials....)</p> <p>Employees (metro and museum)</p> <p>Users (metro and museum)</p>
Assisted Technology	<p>Design of the different phases of the process in easy reading</p> <p>Design of the different phases of the process in accessible format</p> <p>Use of evaluation probes adapted to the characteristics of the team</p>