Learnings and Benefits from Co-Researching: Views of Advisors with Intellectual Disabilities

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Abstract: The Convention on the Rights of Persons with Disabilities recognizes the value of the contributions these individuals can make to well-being and diversity, and thus the active role they must play in research on their lives. This study aims to investigate the perspectives of people with intellectual disabilities who were part of an Advisory Committee that has been collaborating in research for 9 years on what they learnt and what the research experience meant to them. Their opinions were analysed through individual interviews, focus groups, and the revision of more than 297 written and visual documents produced during the last 9 years. Participants reported significant learning related to the research process, as well as socio-personal learning. Moreover, they reported the increase of their sense of belonging to a socially valued group, enrichment of their social networks and a gain in personal well-being. Beyond contributing to the conduction of research based on the people’s needs, the involvement of people with intellectual disabilities in dissemination actions addressed to the professional field and social policies is deemed as a necessary action in order to make their role in social change more visible.

Keywords: inclusive research; intellectual disabilities; participatory research; social justice; social inclusion

1. Introduction

Inclusive research was defined for the first time as an approach that involves people with intellectual disabilities as more than just an object of study [1]. Subsequently, it was added that they should collaborate in the design, data collection, analysis and dissemination of the results [2]. This research model maintains that people with disabilities have relevant, unique personal experiences, so they must be included in the research as active participants in decision-making about the research process and in the construction of knowledge. Recently, the latter definition was updated, underlining the added value of inclusive research by the following elements: contribution to social change; based on experience to inform both processes and results; research that recognizes and communicates the contribution of people with intellectual disabilities; that provides information that can be used by people with intellectual disabilities to advocate for changes that benefit others; and in which all those involved support those whose issues and circumstances are being explored or investigated [3].

The commitment to ensure the inclusion of persons with disabilities in all areas affecting their lives is supported by the Convention on the Rights of Persons with Disabilities (CRPD) [4]. The CRPD states in its preamble “the value of the contributions that persons with disabilities can make to general well-being and diversity” (point m), and that persons with disabilities should have the opportunity to actively participate in decision-making processes on policies and programmes that directly affect them (point o). Article 8 encourages “awareness of the capacities and contributions of persons with disabilities”. It is stated that they must be able to participate in monitoring the development of the Convention (art. 33) and that it must be ensured that research is accessible to them (art. 31).
Since the beginning of the 21st century, inclusive research has been developed in which people with disabilities have played a role as advisors, co-investigators or leaders of research processes [5]. Recently, some consensus was reached on the main points to take into account when designing and developing inclusive research [6]. These points are shaped in a statement which addresses: attributes (e.g., recruiting researchers, how to make the study as inclusive as possible), potential outcomes at several levels (e.g., personal, professional, research), reporting and publishing (which describe and explain why an inclusive research process was chosen, how decisions were made during the research, how support was provided to all team members), and future research directions (exploring the power relations between researchers with and without intellectual disabilities, and exploring how and why inclusive research adds value to research). Some analyses that address some of these mentioned attributes have been carried out on the contributions of this type of research [3,7,8], but there are few studies focused on the perceptions of people with disabilities participating in inclusive research processes [9–16]. Some literature has collected the views of researchers with intellectual disabilities, and it shows that their perceptions focus on different topics, as detailed in the following lines. On the one hand, the conditions for carrying out inclusive research have been analysed by several studies [10,12,13,17,18], highlighting the need to establish a climate of trust in a safe space, where communication is favoured. On the other hand, other researchers [10,18–20] have stressed the need to build a collaborative relationship in which each person involved feels they can contribute. Then, another topic investigated is the support to researchers with disabilities [10,18,19,21], related to accessibility to the materials, activities and processes involved in the research, and also related to power, since the lack of accessibility can disempower the person and deter them from participating. At the same time, the benefits for participants with intellectual disabilities in inclusive research have also been studied [9,11,13–16,18,19,21,22].

In 2012, the Diversity Research Group of the University of Girona decided to invite people with Intellectual Disabilities to form part of an Advisory Committee (AC) in order to include their opinions and points of view in the choice of topics and in the organization of research, and to achieve research closer to their interests and concerns. The Advisory Committee, made up of a number of people ranging over time from 6 to 12, has been in regular activity since the academic year 2012–2013. The activity of the Advisory Committee has evolved over time and collaboration with the research group has intensified.

During these 9 years of operation, the perceptions of the members of the Advisory Committee on their participation in advisory activities, collaboration, and even management of research on issues related to disability have been compiled. The objective of this article is to show, based on a documentary analysis of the material collected throughout nine out of ten years of the Advisory Committee’s operation, the voices of researchers with disabilities regarding what their participation in the development of research processes at the university has represented for them: what they learned, how they value their learning, and how they perceive their own contribution in these processes. In doing so, we want to contribute to valuing the role played by people with disabilities in creating and mobilizing knowledge about issues that affect them, and to advancing the promotion of their own rights. Going into greater depth into this theme will allow evaluation of the inclusive research model by exploring the different dimensions that the participants in these processes value as more relevant for their learning and their achievements, both personally and collectively.

2. Method

2.1. Context: The Advisory Committee of the Diversity Research Group of the University of Girona

During the 2012–2013 academic year (year 1), the research team formed an Advisory Committee composed of ten adults with intellectual disabilities. The richness of both the process and the results of this incipient collaboration led the group to give continuity to this collaboration and increase it both in intensity and frequency, which allowed different forms of collaboration to be established over time.
The working procedure followed with the Advisory Committee has been based on monthly meetings (bimonthly in some periods) from September to June. Each meeting lasts about three hours, on Thursday afternoons, at the university, and it starts with an informal space having some drinks and snacks while being able to socialise. Academic researchers give support to the advisors in each of the working sessions, but the advisors are the ones who make the main and final decisions. At the beginning of each academic year (September), the researchers present an informed consent document to the members of the committee, explaining what the Advisory Committee is, requesting their commitment to participate at least during the current academic year (September–June) and explaining that some sessions will be recorded in audio or video in order to document the work done. The document requests authorization to make these recordings and use the content of these recordings for the sole purpose of disseminating the activity of the committee, and it also states the possibility to withdraw from the committee at any moment. Once explained, each of the members signs the informed consent document. Most of the meetings have been video recorded by the researchers with the consent of all the co-investigators, a fact that has made it possible to document the entire process. During the meetings, the researchers offer different support to the advisors, depending on the objective of each meeting and the type of collaboration carried out. These supports have been, for instance: the preparation of the material of the meetings in accessible format; the preparation of accessible minutes that describe what has been worked during each session, the dynamization of the discussion sessions, proposing and explaining some topics, materials and procedures to work with; facilitating the access to some research elements (such as scientific articles, data collection instruments, the data obtained, etc.); and the joint preparation of dissemination materials on the work carried out, among others.

Table 1 summarizes the main activities developed by the Advisory Committee, differentiating those that were developed mainly from the advisory modality, those that were carried out from the collaboration model and the individual research developed based on the initiative of the advisors, with the support of the academic researchers.

<table>
<thead>
<tr>
<th>Year</th>
<th>Advising Research</th>
<th>Collaboration as Co-Researchers</th>
<th>Leading Own Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (2012–2013)</td>
<td>Research on transition to adult life</td>
<td></td>
<td></td>
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<tr>
<td>2 (2013–2014)</td>
<td>Independent living research</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 (2016–2017)</td>
<td>-Master’s degree final project on university inclusion</td>
<td>Research into the guardianship process</td>
<td></td>
</tr>
<tr>
<td>6 (2017–2018)</td>
<td>-Project on self-determination in the digital age</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-Museum accessibility guide</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>of COVID-19 on the rights of</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>people with disabilities</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(communication presented at</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Conférence Alter 2021, France)</td>
<td></td>
</tr>
<tr>
<td>8 (2019–2020)</td>
<td>-Thesis on support for siblings of young people with Down syndrome</td>
<td></td>
<td>Research into the gaze of the other</td>
</tr>
<tr>
<td></td>
<td>-Quality Framework for the construction of good practices (research on personal support networks) [25]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 (2020–2021)</td>
<td>Course on rights for people with disabilities</td>
<td>Research on the right to social relationships [26]</td>
<td></td>
</tr>
</tbody>
</table>
2.2. Participants of the Advisory Committee

In the last nine years, a total of 35 people with intellectual disabilities have participated in the Advisory Committee; 20 are men and 15 women between 19 and 60 years of age. On average, the Advisory Committee is composed of about 11 people each year. As participation is voluntary, its duration varies depending on the interests of the person, their employment status or other reasons. Most of them (n = 17) collaborated for one year in the Advisory Committee, 3 did so for 2 years, 11 between 2 and 5 years and 4 collaborated for more than 5 years.

The contact with potential advisors is carried out every year through the collaboration of professionals who provide support to people with intellectual disabilities for their social and labour inclusion from different organizations. To select potential candidates, the following requirements apply: (1) that they are adults with intellectual disabilities; (2) that they have sufficient autonomy to travel to the university (where the meetings take place), and (3) that they have interest and motivation to participate in discussions on issues related to their lives and their rights. Efforts are made to ensure the balance of men and women, seeking representation of different ages and educational and employment paths, among others. Even so, over the years, word of mouth among people with intellectual disabilities themselves has contributed to publicizing the Advisory Committee’s project and directly contacting those people who have shown interest in participating.

2.3. Materials Analysed

This study aims to investigate the perspectives of the participants in the Advisory Committee that has been collaborating in research for 9 years, on what they learnt, what the research experience meant to them, and how they perceive their own contribution in these research processes. Throughout the last 9 years, the activity of the Advisory Committee has been documented through written and audio-visual documents: meetings minutes, meetings transcripts, informative videos produced by the members of the Advisory Committee, murals elaborated during the working sessions, videos recorded during the working sessions, a poster presented at an international congress, questionnaires answered by the members of the Advisory Committee in relation to the training received on research, and individual interviews with the members of the Advisory Committee. Those short individual interviews had the aim of gathering their perceptions regarding their own contribution to the research processes in which they had been involved. All these documents (297) constituted the data corpus. In order to learn about the lessons learned by the members of the Advisory Committee and their perceptions of their experience as researchers, all available documents were screened to identify those containing information on how advisors with intellectual disabilities valued their experience as researchers and what learnings they did. A set of 50 documents were selected to be submitted to a thematic analysis [27]. Subsequently, specific fragments containing specific information on the lessons learned and perceptions of the research experience were selected. Almost all the material was written documentation from which excerpts were selected in which participants provided perceptions of their experience and learning through participating in the Advisory Committee. In the case of videos, the fragments that matched the objective of the analysis were transcribed. In the case of questionnaires, only some open questions were selected. The participants’ answers referring to their opinions and perceptions were included in the analysis. Working documents like slides with summary of ideas, or photographs of the work done during sessions, such as wall posters, were selected when they contained information related to the aim of the analysis. A congress communication and a scientific article [23] about the work developed by the Advisory Committee were also analysed. Table 2 shows the total of documents of each type that constituted the analysis material indicating the number of documents that were selected for analysis.
Table 2. Synthesis of the materials analysed.

<table>
<thead>
<tr>
<th>Document</th>
<th>Year 1</th>
<th>Year 2</th>
<th>Year 3</th>
<th>Year 4</th>
<th>Year 5</th>
<th>Year 6</th>
<th>Year 7</th>
<th>Year 8</th>
<th>Year 9</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T</td>
<td>A</td>
<td>T</td>
<td>A</td>
<td>T</td>
<td>A</td>
<td>T</td>
<td>A</td>
<td>T</td>
<td></td>
</tr>
<tr>
<td>Meeting minutes</td>
<td>6</td>
<td>5</td>
<td>8</td>
<td>1</td>
<td>6</td>
<td>1</td>
<td>8</td>
<td>1</td>
<td>7</td>
<td>64</td>
</tr>
<tr>
<td>Meeting transcripts</td>
<td>5</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>15</td>
</tr>
<tr>
<td>Outreach videos</td>
<td>11</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Murals made in work sessions</td>
<td>21</td>
<td>13</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>19</td>
</tr>
<tr>
<td>AC Member Individual Interviews</td>
<td>31</td>
<td>21</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td></td>
<td>19</td>
</tr>
<tr>
<td>Posters presented at congresses</td>
<td>11</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Communications presented at congresses</td>
<td>14</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>10</td>
</tr>
<tr>
<td>Scientific articles</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Book chapters</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Working documents used during meetings (PPT, images, cases)</td>
<td>11</td>
<td>8</td>
<td>4</td>
<td>9</td>
<td>10</td>
<td>16</td>
<td>10</td>
<td></td>
<td></td>
<td>65</td>
</tr>
<tr>
<td>Photographs of work done in meetings (murals)</td>
<td>12</td>
<td>10</td>
<td>1</td>
<td>10</td>
<td>11</td>
<td>1</td>
<td>11</td>
<td>19</td>
<td>12</td>
<td>86</td>
</tr>
<tr>
<td>TOTAL</td>
<td>297</td>
<td>50</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

T = total; A = analysed; light grey columns = material analysed; dark grey columns = total amounts of material available and analysed.

2.4. Data Analysis

A thematic analysis of the selected fragments was carried out using an inductive approach. One of the authors codified the data set using descriptive coding [27], that is, assigning a short word or phrase to summarize the ideas of each fragment. Another of the authors reviewed the work, adding new codes when necessary. Finally, a third author reviewed the coded data set, taking into account the final version of codes, and completed the coding process. When doubts arose, the authors discussed the codes together and agreed on them. The resulting codes are shown in Table 3. This procedure led to a full description of the data in order to capture the participants’ views on how they valued and what they had learned from their participation in the Advisory Committee.

Table 3. Codes and subcodes used for documentation analysis.

<table>
<thead>
<tr>
<th>What Does Being a Member of the Advisory Committee Mean?</th>
<th>Codes</th>
<th>Subcodes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sharing your own experience</td>
<td></td>
<td>-Discover other opinions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-About the research (process, phases, methods, instruments or techniques)</td>
</tr>
<tr>
<td>2. Learn</td>
<td></td>
<td>-Things that help in one’s life</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Learn from everyone, value diversity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Crossroads of knowledge</td>
</tr>
<tr>
<td>3. Socialize</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Contribute to the change and improvement of knowledge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Social valuation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Sharing/being part of a safe space where you feel respected</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Discussion on topics of interest to oneself</td>
<td></td>
<td>-Making decisions on subjects to work on</td>
</tr>
<tr>
<td>8. Impact that we would like the research we do to have</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3. Results

The presentation of the results is carried out in accordance with the codes and sub-codes established in the analysis, and is accompanied by quotations from the members of the Advisory Committee. It specifies in which document and year the above-mentioned opinions were collected.

3.1. Sharing Your Own Experience

The members of the Advisory Committee stressed that one of the relevant factors of their participation in research was to share their own experience with other people, as well as knowing different experiences of their colleagues. They agreed on the great value they attach to being able to express their feelings and views that they cannot express in other contexts. They appreciated the support of their peers and the respect shown among them when expressing their opinions.

At first I was very shy, but over time I opened up and explained how I felt, and I really liked it. (advisor, meeting transcript, year 4)

Another aspect highly valued by the advisors is the possibility to express their opinions. Not only because they consider it important to be able to give their opinion and listen to different perspectives, but also because it is something that allows them to feel well. They also mention the importance of showing respect when expressing their opinions.

A very positive experience because I have been able to express myself and listen to different opinions about what I think and what others think, and being able to do it is very important. (advisor, informative video, year 2)

3.2. Learn

Members of the Advisory Committee appreciated the opportunity to share diverse views among themselves as a source of learning. They noticed several differences between them, whether in points of view, age, or opinion, among others; and they valued this existing diversity, since it allows them to acquire knowledge about different social generations, or about life experiences that they have not yet experienced but would like to.

You learn things from what your colleagues tell you, from the experiences they have lived, you learn from others. So, even if you have not experienced it, you can learn about how it is. (advisor, transcript meeting, year 5)

It has helped me to understand the changes that have taken place in the family, in school, in friends... With this research that we did, now I am considering things in a different way. There are many experiences, of people of different ages, and you learn from them, becoming well prepared to make decisions. (advisor, video transcript, year 1)

The crossing of knowledge between academic researchers and the Advisory Committee was also welcomed: the knowledge in which the academic researchers are experts (research processes), and the knowledge that belongs to Advisory Committee members (the experience of living with a disability). Thus, the members of the Advisory Committee affirm themselves as being experts on the basis of experience.

You (academic researchers) also learn from us. (advisor, informative video, year 5)

In the richness of university work, all points of view must be taken into account: the researcher’s point of view and the advisory point of view, as we have advised. (advisor, informative video, year 2)

When it comes to disability, what better teachers than us? (advisor, meeting transcript, year 5)

The members of the Advisory Committee also indicated lessons learned about the research process itself: the phases in which it is distributed, the different methods that can be used, various techniques and tools for data collection, etc. This implies the acquisition and development not only of theoretical knowledge, but also of competences linked to research.
An investigation is a process, you need planning. Differences are seen at different times of the investigation; you ask yourself questions, you give your opinion... (advisor, questionnaire, year 2)

In addition, participation in research also provided Advisory Committee members with useful learning for their daily lives, now or in the future.

Working on the topic of life as a couple is a help for people who have never done so. Knowing the pros and cons can help someone, tomorrow, to live better. (advisor, informative video, year 5)

It has helped me, because it’s a bit complicated with the partner, and talking about it with everyone has helped me to know how to do it; it is good to talk about it with everyone. (advisor, meeting transcript, year 4)

However, it is not only about current daily life issues or about possible life projects, but also about the development of personal skills, such as social and communication skills, for instance.

Here I have learned to intervene, to say things and to open up more to my colleagues, to respect my colleagues, and also to get rid of my shame. (advisor, video transcript, year 1)

3.3. Socialize

Socialization opportunities were also mentioned as one of the positive aspects of participation in the Advisory Committee. Having fun and having a good time is something on which all the members of the Advisory Committee agree and say that their participation in research allows them to get away from their routines. In addition, they highly value the space dedicated to leisure prior to the work sessions.

(...) it is different from what I normally do, (...) I get out of the routine, doing something I like, that I enjoy and learn. (advisor, meeting transcript, year 1)

In addition, some of them claimed to have established friendships with some of the group's colleagues.

3.4. Contribute to the Change and Improvement of Knowledge

The members of the Advisory Committee valued their contribution to the advancement of knowledge regarding the lives of people with intellectual disabilities, and their contribution to social change in relation to improving the lives of people with intellectual disabilities.

We can bring many things to the table from our own experience. (...) People who don’t know anything (about disability) can’t give advice as we do. (advisor, meeting transcript, year 5)

The members of the Advisory Committee consider their own life experiences, views and opinions to be crucial for academic researchers to be aware of the reality of persons with intellectual disabilities, so that the research carried out is based on their realities, as well as their interests and needs.

We bring them face to face with reality (to the academic researchers). (advisor, meeting minutes, year 5)

In any case, not only does the academy benefit from the participation of people with intellectual disabilities in research, but there is also a positive impact on society. Both people with disabilities and professionals working with and for them can benefit from the different advances in research related to the lives of people with intellectual disabilities.

The important thing is that the professionals have benefited from the studies we do. (advisor, questionnaire, year 2)
In addition to their social service undertaken, the members of the Advisory Committee also expressed the benefits that they can bring themselves to the people in their closest circle, as they can give them advice, or motivate them to participate in research.

_Here you learn many things. And if later a friend of yours has any doubts, you will be able to give him better advice._ (advisor, video transcript, year 5)

### 3.5. Social Value

According to the members of the Advisory Committee, participation in research allowed them to feel useful, important and socially valued. They are aware that both their collaboration and their active participation in different research activities are useful and can generate social benefits.

*I feel important. I contribute. In other places, they would not listen to us as they listen to us here._ (advisor, interview, year 6)

In addition, this social value was perceived by the members of the Advisory Committee when they realized the prejudices that they have helped to break/overcome by regularly attending a university institution. According to some of the advisors, the people in their social circle had never believed that they would ever participate in a university context.

_It’s an honour for me to come here to the university. Go to university… Who would have imagined that? Coming to college is an honour, and that they count on you is an honour._ (advisor, meeting transcript, year 1)

_My family didn’t expect me to come here to the university._ (advisor, meeting transcript, year 5)

### 3.6. Sharing and Being Part of a Safe Space Where You Feel Respected

Another aspect highly valued by Advisory Committee members was the opportunity to be part of a group of people who are valued and respected. They attach importance to the good group atmosphere and feeling included in the group.

_It’s a little therapeutic too, because you don’t feel special, you feel in a very united group, very cohesive…_ (advisor, informative video, year 2)

The members of the Advisory Committee also concurred with the idea that it is a group of people and a space in which they can vent and express themselves freely, relying on the people to whom they open up and express their feelings, thoughts and ideas.

_Here we speak more confidently than with other people. We can talk about more personal things._ (advisor, meeting transcript, year 5)

In addition, some of the members of the Advisory Committee stated that being able to share their personal experiences allowed them to feel helped by their colleagues, since they expressed their perspectives, allowing them to assess different possible solutions to a personal conflict. Likewise, they showed the equal treatment that exists among all members of the group, which they do not always receive in other social contexts.

_(…) explain things, because then others can tell me how I can do it to do it well, help me to do things well and think a little differently._ (advisor, meeting transcript, year 4)

### 3.7. Discussion on Topics of Interest to Oneself

The members of the Advisory Committee stressed the importance of being able to choose the topics on which they carry out their research. In general, these are issues of interest to them, but, mainly, they agree that these are usually issues that they cannot discuss or talk about in other contexts or environments in which their lives develop and therefore decide to investigate them as soon as they have the opportunity.

*I use research to discuss topics that interest me._ (advisor, individual interview, year 7)
(Academic researchers) Ask us what topics we are interested in, and we vote on which to research. (advisor, individual interview, year 7)

More specifically, the members of the Advisory Committee believe that there is a direct relationship between the topics they decide to investigate and their personal interests and day to day needs. They decide to research topics with which they feel identified, or life situations that are familiar to them. They think that what they learn by researching is useful in their lives.

I was able to understand the situation of leaving home, when I found myself in that situation. (advisor, meeting transcript, year 5)

3.8. Impact That They Would Want the Research They Carry Out to Have

As for the impact that the members of the Advisory Committee would like to have with their participation in research, it is mainly to make people with intellectual disabilities visible, and to convey the idea that they have many abilities. They want society to treat them well, respect them and believe in their many possibilities. They believe that their participation in research can contribute to the reduction of both misunderstanding and discrimination suffered by many people with intellectual disabilities.

Make people with disabilities more visible. (advisor, meeting minutes, year 5)

It would be nice if people thought we have possibilities. (advisor, meeting transcript, year 5)

One way to promote that society becomes more respectful towards people with intellectual disabilities would be by giving them the opportunity to be recognized; being aware of the research work they develop and valuing it, for instance. In this way, society could not only value them more, but also learn from them. The members of the Advisory Committee wish to continue to contribute to change and to the improvement of knowledge in order to generate social change and improvement.

I think that, of barriers, they are always going to give us barriers, because we are these types of people in particular, that we have a difficulty. I believe that, in a few years’ time, companies and society as a whole should look at these issues from a different point of view. If these people have this difficulty, then help them more, do not say no from the outset. Participating in the Advisory Committee is a way to break down these barriers, because people are telling each other, and it is a way to reach all people. (advisor, informative video, year 2)

4. Discussion

There are few studies focusing on the experiences, opinions and perceptions of people with intellectual disabilities involved in inclusive research. The experience of inclusive research carried out jointly with the Advisory Committee over the last 9 years allows us to confirm, through the analysis of varied sources, the perceptions of its members on participation in research processes. The members of the Advisory Committee presented in this article demanded that the investigations carried out be based on their realities, as well as on their interests and needs. They recognized that both their life experiences and their views and perspectives are necessary for academic researchers to learn about the reality of people with intellectual disabilities. Coinciding with the idea of research as a meeting point between researchers with and without disabilities in which everyone learns [28], the participants in the study referred to the crossing of knowledge existing between academic researchers and themselves: the former provide knowledge about research processes, while the latter contribute knowledge from their position as experts by experience.

The results coincide with previous studies regarding the relevance that people with intellectual disabilities give to the central topic of the research to be carried out [12,17]. They should be subjects of personal interest to them, and directly related to their day to day needs. Thus, they often prefer to research matters with which they feel identified or life
situations that are familiar to them, so that their participation in the research allows them, at the same time, so learning acquired is useful in their lives. Sharing diverse opinions and experiences is perceived as a source of learning by Advisory Committee members. These results coincide with previous literature that argues that participation in inclusive research allows people with intellectual disabilities to acquire knowledge about the topics being studied [13]. In addition, as with the participants of another research study [22], this study demonstrates that researchers with intellectual disabilities have acquired useful knowledge for their daily lives: by sharing personal experiences among everyone, they have managed to better understand their own lives. They say that when they share their personal experiences they feel helped by their peers, and that it is crucial to be able to express themselves freely and with confidence with the people with whom you share research. These results coincide with those obtained in other studies [10,13,17,18,22], which highlight the importance of being able to carry out inclusive research in a climate of trust, with respectful attitudes, and in an environment of mutual help.

Participants in the Advisory Committee also stated that they had learned about the research process, such as the research process itself and the use of different techniques and tools for data collection and analysis. There are some previous studies [9,11,12,16] that agree that participation in inclusive research allows people with intellectual disabilities to learn and/or improve their research skills.

The socialization of participants in inclusive research groups [11,14,22] is another of the aspects valued by the members of the Advisory Committee. Some of them claimed even to have established friendships with some of the group’s colleagues. This coincides with the results of a study [21] in which it is stated that the constitution of the group and the friendships that are established are as important for people with intellectual disabilities participating in inclusive research as issues related to the research.

Specifically in our context, the participants in the Advisory Committee perceived the usefulness of the research they carried out, so they feel socially valued. This is partly because they are aware that the work they do can help other people [9,11,18]. However, there was a significant difference from previous studies where they had affirmed that participation in inclusive research improves the perception of people with intellectual disabilities about their own ability to contribute significantly in their communities [14,19]. In contrast, in this study the members of the Advisory Committee did not state either strongly or repeatedly the benefits that they can bring with their participation in the research to all people with intellectual disabilities and/or to the professionals who work with them; nor their ability to influence practices and policies that can improve their lives and the exercising of their rights (as stated in another existing study [15]). This suggests that actions should be taken to help the researchers with intellectual disabilities from the Advisory Committee of the Research Group in Diversity of the University of Girona to increase their awareness of their contribution to improving knowledge about the lives of people with intellectual disabilities and, in so doing, to highlight their potential contribution to the transformation of their living conditions. It is also advantageous to carry out the necessary actions that allow these contributions to be valued by the entire academic community and by society in general. One of the factors that could contribute to this is a plan to disseminate inclusively conducted research in which advisors are actively involved. Currently, there is an imbalance in the participation in knowledge mobilization activities between academic researchers and researchers with disabilities [15], since the latter enjoy fewer opportunities to participate in congresses, publish in scientific journals and, in general, access the processes involved in the development of dissemination activities.

5. Conclusions

For almost a decade we have been working together with the researchers who have served on the Advisory Committee, and with them we have had the opportunity to learn about disability. The direction developed in inclusive research has also influenced us in how we understand and carry out research within our group and in the collaborative relationships
we want to establish between us, with people with disabilities, and with the professionals who support them. In this sense, developing inclusive disability research processes, collaborating and/or supporting researchers with intellectual disabilities, means creating a core of research that provides a more fertile and divergent context in the construction of knowledge [29]. To academic researchers, these processes teach us to transform our research methods by making them more accessible, to be creative and thus to incorporate in our research and teaching work other ways that enhance interaction and the creation of knowledge.

The results obtained in this study coincide for the most part with the perceptions made by researchers with intellectual disabilities in previous research carried out internationally. This underlines the value of inclusive research for researchers with intellectual disabilities involved in these processes. This particular research study has shown that researchers with disabilities do not seem to have a widespread awareness of their potential social contribution, while they do recognize learning in the field of knowledge, methodology, and social relations. In Spain, there are few groups of self-advocates, and the vast majority of them are linked to support organizations, so many of their members did not have the opportunity to regularly discuss and defend their rights. Possibly, this specific context influences their lack of awareness about their social contribution through the research that was found in this study. This implies the need to insist on the support of researchers with disabilities who are experts for their experience of said disability so that they are aware of their necessary and relevant contribution to knowledge, insisting on different lines of action. First of all, prioritising the empowerment of the members of the Advisory Committee by going in-depth into their rights. This could be developed through spending more time during the different working sessions to know in detail the different rights linked to the research being developed. It is also important that the members of the Advisory Committee actively participate in disseminating the results of the research. In this sense, specifically in our group, we propose to jointly plan dissemination actions, diversifying addressees and including dissemination actions in the social services which would be aimed at professionals as well as families and other people with disabilities. All members of the Advisory Committee should participate in such dissemination activities. Such activities can definitely help to create an inclusive culture of research focused on rights that helps people with intellectual disabilities to be aware of their power to change and improve their living conditions.

Other aspects that would contribute to a greater awareness and empowerment of the researchers with disabilities in our group would be that they received financial compensation for their contribution to the research, and also increasing the frequency of the meetings we develop. The first issue, clearly related to the social recognition of the role of researchers with disabilities, will be negotiated with the university administration; the second, which would allow greater continuity and involvement of the advisors, depends on their availability, and it will be discussed with them during the next academic year.

The study does have its limitations. On the one hand, although the amount of documentation analysed is considerable, considering that nine years of activity of the Advisory Committee have been documented, it should be noted that this committee has been constituted by people with intellectual disabilities with limited or intermittent support needs. We cannot, therefore, claim that the results would be similar in the case of the participation of people in great need of support. On the other hand, although many results are aligned with results found from work done by other inclusive research groups, the analysis presented here focuses on the experience of a single inclusive research group, with a remarkable trajectory, but a single group, after all. However, the contributions, although unique, can be relevant both for the group itself and for other groups that work or want to work from the perspective of inclusive research. Finally, although the analysed materials derive from the activity of the Advisory Committee over 9 years, the advisors with intellectual disabilities have not been involved in the process of analysis and writing of this article. This constitutes a limitation, despite that the authors have tried to be as faithful as possible to the contributions of the advisors. This last limitation provides the authors with a great need of
reflecting on how this article has been developed, considering the necessity of including the members of the Advisory Committee in a discussion about their lack of involvement in it.


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