



Article

Relationships of People with Intellectual Disabilities in Times of Pandemic: An Inclusive Study

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Abstract: (1) Background: Since 2012, our Inclusive Research Team has developed several studies on various topics that interest the co-researchers with intellectual disabilities. In 2021, throughout the COVID-19 pandemic, the co-researchers decided to investigate the impact of the pandemic on the relationships of people with intellectual disabilities. The aim of this article is to disseminate how this inclusive study was developed and to explain its results; (2) Methods: Co-researchers and academic researchers met six times to make different decisions: decide on the research topic; discuss the topic; prepare an interview script for people with intellectual disabilities; analyse the data obtained; and decide how to disseminate the results of the research. The co-researchers interviewed 10 people with intellectual disabilities and participated as facilitators in 3 focus groups; (3) Results: During the pandemic, digital devices have enabled people with intellectual disabilities to maintain their social relationships. However, the lack of access or support in using them, as well as the restrictions imposed on people with intellectual disabilities living in institutions, have presented significant barriers to maintaining their social relationships; (4) Conclusions: This article shows the difficulties people with intellectual disabilities face in maintaining successful social relationships in times of pandemic, and how we undertook research in an inclusive, virtual manner.

Keywords: intellectual disabilities; inclusive research; pandemic; relationships



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1. Introduction

1.1. The Advisory Committee of the "Diversity Research Group"

In 2012, the "Diversity Research Group" constituted an Advisory Committee made up of 10 adults with intellectual disabilities. The objective was to record their opinions and experiences on the transition to adult life, the subject of the research project that was being developed at that time. In this way, a collaborative relationship began in which people with intellectual disabilities advised the researchers and helped them make decisions in the different phases of the study. The richness of the process and the results of this incipient collaboration (Puyaltó et al. 2016) led the group to continue with this collaboration and to increase both its intensity and frequency, developing the three main forms of collaboration recognized in inclusive research (Bigby et al. 2014): advisory actions (for example in a research on transition to adulthood, see Fullana et al. 2016; Pallisera et al. 2015); co-research (for example, in research on independent living, see Pallisera et al. 2017), and leadership of some of the research processes developed (such as life as a couple, see Puyaltó et al. 2019). Rooted in the participatory and emancipatory research paradigms, the inclusive research model (Walmsley 2001, 2004; Walmsley and Johnson 2003) encourages research conducted by people with disabilities and argues that people with relevant experience in relation to the studied topic should be included in the research and their participation facilitated in all

phases of it, as a necessary way as a way of respecting their right to actively participate in matters that concern them.

The working procedure followed by the Advisory Committee (AC) is based on monthly meetings (bimonthly in some periods), lasting about three hours, on Thursday afternoons, at the university. Each meeting begins with an informal time of approximately one hour, so that all the participants (researchers and co-researchers) can catch up and have a snack together before starting work. During the meetings, the researchers offer different forms of support to the co-researchers, depending on the objective of each meeting and the type of collaboration carried out: preparation of the meeting material in an accessible format, preparation of accessible minutes, facilitation of the debate sessions, and joint preparation of materials for dissemination of the work carried out, among other forms of support. Most of the meetings have been video recorded by the researchers with the consent of all the co-researchers, something which has made it possible to document the entire process. A total of 35 people has formed part of the AC over almost 10 years. Each academic year, the Committee is composed of between 10 and 12 people. Participation is voluntary, and participants decide about their continuity in the AC depending on their interest and availability.

1.2. The Impact of the COVID-19 Pandemic on Personal Relationships

The World Health Organization declared COVID-19 a global pandemic on 11 March 2020. Measures such as mobility restrictions and social distancing were adopted in all countries. The government of Spain declared a State of Emergency ([Real Decreto 463/2020](#)) as a mechanism to legally impose home confinement measures. Daily life was greatly disrupted, especially between 15 March and 21 June 2020. Since then and during the first six months of 2021, contagion control measures were maintained, entailing restrictions in terms of the number of people in social gatherings and mobility restrictions in the worst moments of the pandemic.

This situation affected university life and, therefore, the activities of the AC, which was affected both in its way of working and the research topics undertaken. The collaboration between the research group and the AC was uninterrupted, but all the activities (the meetings and the application of the instruments) took place online. This adaptation was not without a series of difficulties. These are described in the “Materials and Methods” section of this article.

During the period of confinement, the AC decided to undertake two items of research related to the effects of the COVID-19 pandemic on their lives. The first of them took place from March to July 2020, in a collaborative, inclusive manner ([Walmsley et al. 2018](#)), and aimed to explore the impact of the pandemic on the rights of adults with intellectual disabilities. The second, held between February and October 2021, focused on the impact of the pandemic on the personal relationships of people with intellectual disabilities.

From the beginning, concern regarding the impact of the pandemic on the lives of people with disabilities has motivated the issue of resolutions by international organizations. Some of these refer directly to the issue of interpersonal relations ([European Union Agency for Fundamental Rights \(FRA\) 2020](#); [United Nations 2020a, 2020b](#); [UNICEF 2020](#)). The [United Nations \(2020b\)](#) highlights the negative impact of the pandemic on the social inclusion of people with disabilities, both in their participation in the community and in the establishment of personal relationships with their peers. Concern for the well-being of people living in institutions merits special emphasis, due to the seclusion and resulting social isolation that they suffered throughout the pandemic ([United Nations 2020a](#)).

A large amount of research has been undertaken that addresses the impact of the pandemic on people with disabilities. The voice of people with intellectual disabilities has hardly been considered in this line of research, with some exceptions; Among the studies that do provide the perspectives of people with intellectual disabilities, we should highlight those of [Embregts et al. \(2020\)](#); [Drum et al. \(2020\)](#), [Amor et al. \(2021\)](#) and [McCarron et al. \(2020\)](#). In the Netherlands, [Embregts et al. \(2020\)](#) explore the experiences of six

people with intellectual disabilities during the emergency period, highlighting the increase in their feelings of loneliness, personal discomfort, and the loss of relationships. [Drum et al. \(2020\)](#) surveyed 2469 adults in the US, 930 of whom have intellectual disabilities, autism, epilepsy, or brain damage. Overall, 66% of those surveyed experienced anxiety or depression due to the pandemic, and 20% reported not being able to access support services. Emotional issues grew among respondents over time as the pandemic continued and lack of services/supports made these problems more acute. [McCarron et al. \(2020\)](#) present the findings of Wave 4 of IDS-TILDA, a longitudinal study conducted in Ireland since 2008 which aims to identify the principal influences on successful ageing in people with intellectual disability in Ireland. Wave 4 of this study coincided with the pandemic period and included a COVID-19 questionnaire that was administered to 710 participants with intellectual disability. Some of the main findings indicate that more than half of the participants (55%) indicated stress or anxiety due to pandemic and that the most common cause of it was not being able to do usual activities, not seeing friends/family, loneliness/isolation, and fear of getting COVID-19. Even though people living independently or with family were more likely to report missing friends than those living in residential care or community group homes. Finally, [Amor et al. \(2021\)](#), also explored the perceptions of 582 people with intellectual disabilities during the lockdown in Spain through a questionnaire in which information was collected in relation to: access to information, emotional experiences, effects on living conditions and access to support. The participants reported difficulties on an emotional level, as well as problems to continue working or training. In research as a whole, it can be observed that the subject of relationships has hardly been studied in the research on the impact of COVID-19 on the lives of people with intellectual disabilities.

The objective of this article is twofold: on the one hand, to disseminate how we carried out this inclusive study; and on the other, to provide information on a significant issue for people's lives, focusing on the barriers they have encountered to maintaining their personal relationships and to make proposals for improvements.

In this inclusive study, the role of the academic researchers has been to support the co-researchers throughout the research process. They were supported in choosing, exploring, and discussing the topic, collecting data on the topic through interviews and discussion groups, and analysing the results obtained. The academic researchers were also responsible for organizing the working meetings held with the co-researchers. This article was written mainly by the academic researchers after holding two working meetings with the co-researchers at the end of the research process with the aim of including their voices in this article. In the first meeting, after positively evaluating the possibility of publishing this article and its implications, the co-researchers reviewed the research process carried out and assessed different elements (study topic, methods used, current situation regarding the study topic, etc.). Their evaluations were later analysed by the researchers and included in the article in the form of vignettes. In the second meeting, the researchers presented the different sections of the article to the co-researchers in an accessible format in order to assess their content. They were also shown their contributions in the different sections so that they could decide whether they agreed to include them. Finally, they decided if they wanted to use pseudonyms and if they wanted to participate as authors of the article. The co-researchers agreed with the information provided in the article, they decided to include all the vignettes proposed by the researchers that included their points of view; and they chose their own pseudonyms—these appear in the vignettes that expose comments made by the co-researchers on different topics, such as the methods used in the research ("Materials and Methods" section) or the importance of researching on interpersonal relationships in times of pandemic ("Discussion" section).

2. Materials and Methods

Between September 2020 and June 2021, 11 co-researchers, 6 women and 5 men, aged between 18 and 60, formed part of the Advisory Committee (AC) of the Research Group.

Three of these people joined the Advisory Committee for the first time. The AC had the support of five researchers and a master's student, who were in charge of facilitating the work sessions, taking a note of the agreements reached, helping in the elaboration of the information collection instruments, and providing support to the processes of information gathering and data analysis.

The research was carried out between February and October 2021. Due to the restrictions derived from the COVID-19 pandemic, the work was carried out online, which meant a different way of working compared to what used to be the normal operation of the AC (Figure 1, box 1). The videoconference meetings had the virtue of maintaining the activity of the AC during the time of restrictions (Figure 1, box 2), although technical problems had to be solved (connection, audio, etc.) (Figure 1, box 3) that conditioned some decisions, for example, to work on some phases of the process in small groups in order to facilitate communication between the co-researchers (Figure 1, box 4).

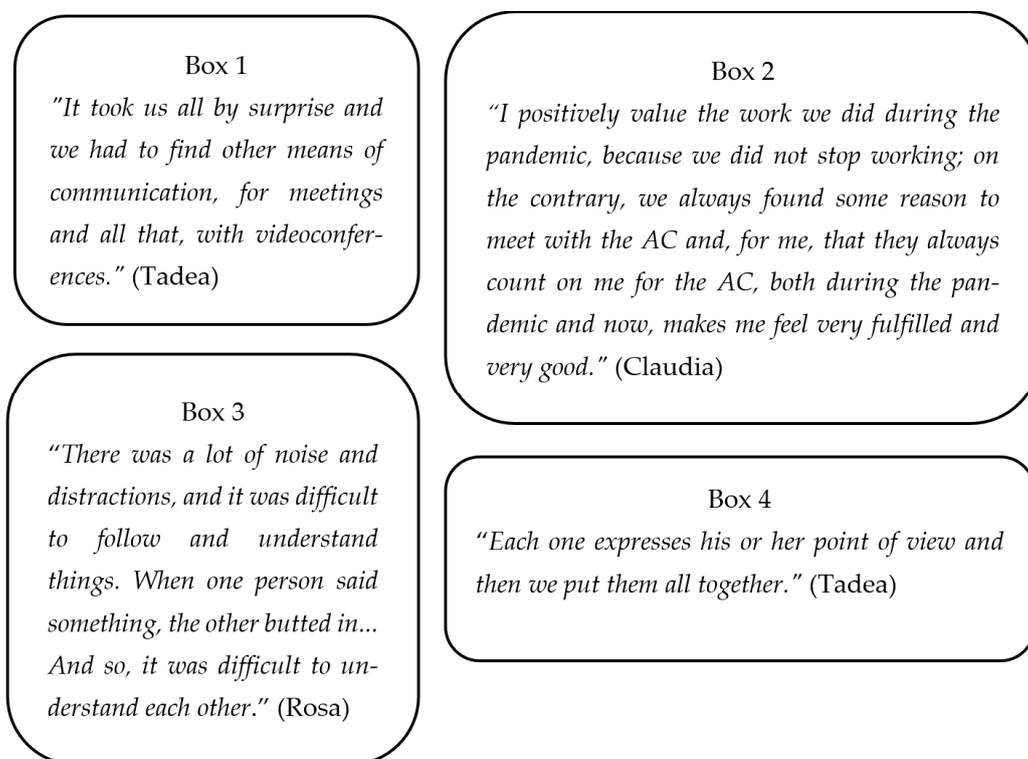


Figure 1. Co-researchers' opinions 1–4.

The process began with a meeting in which possible topics for research were discussed. In this first meeting, the co-researchers were presented and, through a discussion facilitated by one of the researchers, the concerns, themes, and questions that could be the subject of a more in-depth analysis through an inclusive research process were explored. The AC decided to focus its work on social relationships and friendships and how these relationships were affected by the pandemic (Figure 2).

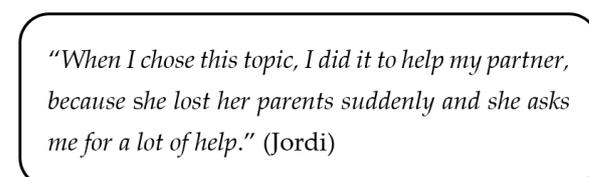


Figure 2. Co-researcher's opinion 5.

The second meeting aimed to explore the experiences of the co-researchers on the research topic. For this reason, two groups were organized working in parallel, with the support of three researchers. Each group was set up as a focus group and they debated about who they usually interact with, what is the role of friends, what difficulties they find in establishing friendships and what or who helps them to establish and maintain these relationships. Part of the debate was dedicated to analysing how the restrictions due to the COVID-19 pandemic were affecting family, friendships, and relationships with partners. The role of new technologies in the pandemic situation in terms of maintaining social relations was also explored. After this analysis, the two working groups showed interest in knowing what other people with intellectual disabilities thought about this issue, so the possibility of conducting interviews was proposed. It was agreed that two people from each group would be in charge of preparing a script for an interview.

In a third meeting, 4 co-researchers with the support of 4 researchers prepared the interview script that included topics such as the type of relationships the person has, the difficulties and supports to make friends, the impact of the pandemic on their own relationships, and the use of new technologies to interact. The team jointly decided on the procedure for collecting the information, including the informed consent of the participants.

Throughout the agreed period, the same 4 co-researchers were in charge of conducting the interviews with some of their acquaintances. They contacted them via WhatsApp and phone calls to inform them about the research and to ask if they would be interested in participating in a virtual interview. Most interviews were carried out through the WhatsApp application audio recording tool. Each co-researcher recorded the questions in audio and sent them to one of his acquaintances with whom he or she had previously agreed to conduct the interview (Figure 3). Before starting the interviews, each participant was informed of the purpose of the research and that his or her anonymity would be guaranteed. Participants were also informed that they were free to answer only the questions they wanted to and could leave the interview at any time if they so wished and their responses would not be used for the project. The person's consent to participate was orally recorded, due to the virtual format. Data were collected from 10 people with intellectual disabilities aged between 18 and 60 years old, of whom 3 lived in group homes and 7 with their parents. The recordings were sent to two of the researchers, who did the transcription of the audio interview tapes. A third researcher analysed the interviews through thematic analysis (Nowell et al. 2017). It was performed question by question. The answers to each question were categorized by topic and summarized in bar charts to facilitate subsequent analysis and discussion with the Advisory Committee.

Co-investigators positively valued conducting interviews with people with ID:

"I think the interviews were very successful, in the sense that they (the people interviewed) even asked us if we had any more questions. The topic fell short." (Jordi)

Conducting the interviews was a personally rewarding endeavour for some co-researchers:

"I thought that the people I interviewed would not participate and, in the end, it went very well, they really enjoyed collaborating and I was able to find out their opinion on this matter. I liked finding out the opinion of people of different ages and with different points of view." (Claudia)

Figure 3. Co-researchers' opinions 6, 7.

In a fourth meeting, the results of the 10 interviews with the co-researchers, who worked in two groups, were presented and analysed. Specifically, the researchers presented the main topics that came up in each question of the interview, indicating in bar charts how often each topic was repeated by the interviewees. Presenting the results in this way made easier for the co-researchers to analyse and discuss the results. During this analysis process, the researchers took note of which topics the co-researchers considered most relevant. These topics were: the value of friendship, the difficulty of making friends without a disability, the importance of new technologies for maintaining relationships, the difficulty of living without physical contact and the lack of freedom to move and see your beloved ones. At the end of the meeting, the researchers proposed to explore the research topic a little more and the idea of holding a focus group with other people with intellectual disabilities arose. Through conducting focus groups, it was intended to obtain more information and, in this way, improve the validity of the results found to date. Two co-researchers showed interest in participating as facilitators of these groups.

The researchers contacted three groups: two groups of self-advocates and a recently created inclusive research group. An accessible e-mail was sent to these groups to explain the aims of the research and request their collaboration in participating in a virtual focus group. All three groups accepted the invitation. In focus group 1, 9 people who made up a group of self-advocates participated. Focus group 2 was carried out with another group of self-advocates in which 11 people participated, and focus group 3 with an inclusive research group made up of 7 co-researchers. Each focus group was facilitated by one of the co-researchers, with the support of two or three researchers (Figure 4). The three focus groups were carried out via videoconference, the same topics were discussed as in the interviews, and the consent of the participants was obtained from all of them, in oral format due to the videoconference process itself. The same procedure was followed to request consent as in the interviews. Once finished, two researchers did the transcription followed by thematic analysis. This analysis was presented and discussed with the Advisory Committee in the fifth meeting.

The role of facilitator of a focus group was a totally new activity for the co-researchers:

"It was a bit difficult for me to moderate the focus group. At first, I was a bit shy because I had never done it before and also, I did not know any of the participants. That is why at the beginning you (the researchers) had to help me a little bit, but then I started to get the hang of it." (Claudia)

Regarding a focus group that was carried out with an inclusive research group from another city, Claudia comments:

"I liked joining this focus group because we already knew the points of view of the people in our city, because we had already done the interviews, and with this focus group we were able to learn how people from other parts of Spain experience this issue" (Claudia)

Figure 4. Co-researcher's opinions 8, 9.

Finally, in order to discuss the results of the focus groups and prepare this article for publication, two working meetings were held with the co-researchers. In meeting 5, 3 co-researchers, with the support of 4 researchers, analysed together the main topics extracted from the focus groups. In that case, to guide the discussion, the summary of the topics

was accompanied by some excerpts from the focus groups. This procedure made it easier for co-researchers to analyse and discuss topics that seemed most important to them. On this occasion, the co-researchers considered that much importance should be given to the situation experienced by people with intellectual disabilities living in group homes during the pandemic. Thanks to the contributions made by the co-researchers during the analysis of the interviews (meeting 4) and the focus groups (meeting 5), the researchers were able to establish a list of final categories and main topics, which are included in Table 1. After discussing the results of the study, co-researchers evaluated the possibility of publishing an article and the research writing process developed. From this meeting, the researchers were able to make headway in the draft of the article incorporating the contributions of the co-researchers.

Table 1. Main topics and categories derived from the analysis of the interviews and focus groups.

Main Topics	Categories
1. The relationships of people with intellectual disabilities before the pandemic	<ul style="list-style-type: none"> • Relationship circles • Benefits of relationships • Limitations and challenges of relationships
2. The opportunities and threats to relationships in times of pandemic	<ul style="list-style-type: none"> • Restrictions to maintain relationships • New ways of communicating • The need of physical contact
3. The impact of the pandemic on the relationships of people with intellectual disabilities who live in group homes	<ul style="list-style-type: none"> • Restrictions in group homes • Social isolation • Human rights violation

In the sixth meeting, the researchers presented the different sections of the article to the co-researchers in an accessible format in order to assess their content. They were also shown their contributions in the different sections so that they could assess whether they agreed to include them. Finally, they decided if they wanted to use pseudonyms in the vignettes that show their opinions and if they wanted to participate as authors of the article.

Table 2 summarizes the process followed to develop the research and prepare this article.

This research was part of a larger project that was ethical approved and authorized by the Spanish State Research Agency who funded the project (protocol code EDU2017-84989-R). Accessible information about the research was provided to all participants and, once they agreed to participate, they gave their consent. Due to the pandemic situation, the informed consents were recorded orally. Data protection legislation was followed throughout the study (Spanish Organic Law on Data Protection 3/2018 and the Regulation (EU) 2016/679 of the European Parliament and the Council, 27 April 2016).

Table 2. Synopsis of the process followed to carry out the research and prepare the article.

Activity	Participants	Tasks and Agreements
Advisory Committee Meeting 1	11 co-researchers, 5 researchers and 1 student.	Presentation of the Advisory Committee Exploration of themes: It was agreed to investigate the impact of the pandemic on the social relationships and friendship of people with intellectual disabilities.
Advisory Committee Meeting 2	11 co-researchers, 5 researchers and 1 student.	Discussion in two groups on the topic of social relationships and friendship.
Advisory Committee Meeting 3	4 co-researchers, 3 researchers and 1 student.	Preparation of an interview script Agreement on the data collection process.
Application of the interviews	4 co-researchers	Conducting the 10 interviews.
Analysis of the interviews	3 researchers	Transcription and analysis of thematic content of the interviews Synthesis of the results through bar diagrams.
Advisory Committee Meeting 4	10 co-researchers, 5 researchers and 1 student.	Discussion in two working groups on the results of the interviews
Focus group 1	Participants: 9 people with intellectual disabilities (7 women and 2 men). Facilitators: 2 researchers	Discussion on how the pandemic was affecting social and friendship relationships
Focus group 2	Participants: 11 people with intellectual disabilities (7 women and 4 men) Facilitators: 1 co-researcher, 1 researcher and 1 student.	
Focus group 3	Participants: 7 people with intellectual disabilities (5 women and 2 men). Facilitators: 1 co-researcher, 2 researchers and 1 student.	
Analysis of the focus groups	2 researchers.	Transcription and analysis of the information obtained through the three focus groups
Advisory Committee Meeting 5	3 co-researchers and 4 researchers.	Discussion on the results of the focus groups Review of the research process followed. Appraisal of the study (theme, methods used, etc.). Appraisal of the current situation
Advisory Committee Meeting 6	4 co-researchers and 4 researchers	Review of the article and suggestions for improvement. Decision making on the authorship of the article.

3. Results

The aim of the research was to determine the opinions of people with intellectual disabilities on the impact of the pandemic on their social relationships. The results presented below derive from the analysis of the information obtained in the three focus groups and in the 10 interviews conducted by the co-researchers. These results are organized around three main themes: the relationships of people with intellectual disabilities before the pandemic, the opportunities and threats to relationships in times of pandemic, and the impact of the pandemic on the relationships of people with intellectual disabilities who live in group homes. To illustrate these issues, verbatim quotes from people with intellectual disabilities are included. All participant names have been changed to pseudonyms.

3.1. Pre-Pandemic Relationships

The people interviewed and those who participated in the focus groups revealed that the people with whom they usually interact, beyond the family nucleus, are friends

with disabilities with whom they share leisure, work, or training activities, and with the professionals who work in organizations that provide them services. Most participants agreed that friends are a valuable source of help. Of the 10 people with intellectual disabilities interviewed, 8 thought that friends can help to understand situations. Three people considered that, in addition, friends help to have fun and overcome problematic and/or conflictive situations. According to the participants of the focus groups, friendship also teaches you to take care of others and be interested in them and put yourself in their place. They agreed that friends help to have fun and be happy. All the participants emphasised that friendship is based on reciprocity.

Lucy: My friends help me, and I help my friends. They ask me how I am, how my family is and so on. Also, if sometimes I don't know how to say something, they help me. (FG2)

All the participants reflected on the difficulties they find in establishing friendships. Most of the people interviewed highlighted the fact of not feeling accepted by others (9 out of 10), feeling different and little understood (8 out of 10). Half of the people interviewed considered that people with intellectual disabilities tend to be seen as inferior by the rest of society.

Rose: Well, before I had a hard time relating, making friends, and for people to accept me, regardless of whether I had a disability or not, because many people did not understand what I was explaining (. . .). Just because of having a little disability, people have a hard time accepting it. (Interview 9, 27 years old)

In the focus groups, it stood out that difficulties in establishing friendships with people without disabilities may be due to other factors such as: having attended a special school and having only related to people with disabilities; the lack of trust that people with disabilities themselves experience towards people without disabilities—especially those who have been victims of bullying; the fear of feeling rejected; and the lack of knowledge and understanding that people without disabilities have about intellectual disability.

Arturo: I interact with the monitors at the centre, with friends, family... with friends from here in the town, no, because I get along very badly with them. I get along better with those in the occupational centre, because they are (people) with disabilities, just like us. Because the non-disabled mess with you, you know? That is why I interact with people from the occupational centre, or with the family: people who love me. (FG3)

Paula: It is true that we relate more to our environment than to other people. Because they don't know how to act with us. So, it is a bit difficult to make friends with people who do not have disabilities. You need to realise that those of us with disabilities do not have friends who do not have disabilities. (FG3)

3.2. Relating in Times of Pandemic: An Opportunity or a Threat?

The pandemic has had a direct impact at different levels on the friendships of people with intellectual disabilities. Some people interviewed emphasised that the pandemic has caused important restrictions, such as not being able to see friends (5 out of 10), their partner (3 out of 10) and some relatives (4 out of 10), especially when they are not part of their own circle of cohabitation.

Regarding the way of relating, online communication was highlighted as one of the main changes that the pandemic has brought about. The physical distancing imposed during home confinement led to increased use of mobile devices and computers in order to maintain contact and communicate with others.

Participants in the focus groups and interviews explained that they had to learn to use applications and platforms such as WhatsApp, Meet, Skype, or Zoom. They positively valued that this learning, in most cases, facilitated by family members and support professionals, allowed them to maintain contact with their friends and family, and continue with their training online.

Gina: *Yes, yes, they have helped me, especially in the foundation to know how a Meet works, or a Zoom or at home they have also been helping me: "look, this is used like this or this like this". To know how to communicate, because in the future I know how to do it better, know how to use them better and not depend so much on other people. (Interview, 27 years old)*

Even so, they stressed that this has not represented a learning opportunity for all people with intellectual disabilities since not all have devices that allow them to access these types of applications and communication platforms, or if they do, they do not all have the necessary support to learn to use them.

Paula: *There are friends from the centre who we cannot see, because they do not have electronic devices. And this is a barrier. Or they don't have an internet connection. Or their parents are older and cannot help them. (FG3)*

In any case, most of the participants agreed that, despite the fact that technology has allowed them to maintain their friendship and partner relationships, they have not been able to meet the need to maintain physical contact with the people they appreciate. In fact, various participants agree that, in the wake of the pandemic, relationships have become considerably dehumanized and have cooled. This has caused distress in some cases and in others, it has posed new challenges such as that of being able to once again experience physical contact with people who were close.

Natalia: *Virtually, you can see your friends and talk to them, and that's fine... But you only see their faces, you can't touch them or hug them... This made me sad. (FG3)*

Martin: *The truth is that it makes me feel strange to be touched after so long... (FG1)*

3.3. Living in Institutions in Times of Pandemic: The Impact on Social Relationships

Although most of the people who participated in the interviews and focus groups live with their families, some live in group homes with other people with disabilities and their support professionals. In these cases, people reported having suffered the effects of the restrictions derived from the pandemic, as well as those imposed by the organizations where they live.

People living in group homes explained that their home confinement was longer than that of the general population. In fact, some of them were confined to group homes for—more than a year—the general population was confined for approximately three months—and with limited mobility to essential activities, such as going to the doctor and other specific actions. This restrictive measure was established during the beginning of the confinement and according to the participants it was imposed to protect them and the support professionals from possible infections. One of the effects of this measure has been social isolation and restriction of freedom of movement.

Joseph: *I have not been able to see my partner for a year. She lives in another group home. (FG1)*

Miguel: *(The confinement) has affected me emotionally, I miss my partner, my family and my friends who do not live in the group home. I hope everything returns to normal... (Interview, 60 years old)*

The participants explained that their activities were also stopped in the day centres, although this was only done for those people who resided in group homes, which meant that the possibilities of social interaction were even more limited for them.

One of the consequences that the pandemic has had for residents of group homes is that activities outside the group home had to be carried out in groups with the accompaniment of a support professional. For the research participants who lived in group homes, this has meant an increase in the already usual restrictions of the institutions since it has led to the loss of contact with friends and family and the loss of autonomy to be able to carry out activities with them. All this has caused a feeling of distress in the residents of the group

homes, who denounce that they have regressed in the exercise of some of their rights, such as making their own decisions or moving freely.

During the last meeting with the Advisory Committee (Meeting 5), two co-researchers living in a group home highlighted the fact that, a year and a half after the pandemic began, some of the results obtained, and described above, on the restrictions on interaction that people with intellectual disabilities experience in the institutions are still in force. This continues to occur despite the fact that almost all restrictions—except for the use of a mask in closed spaces—have now been withdrawn by the administration. In this sense, the co-researchers report that they continue to experience difficulties in meeting their partners and in moving freely outside their home.

Jordi: *They still won't let us go out alone. They only let us out to come to the university. We have to be accompanied by monitors, like dogs. (. . .) They are taking away the freedom we had, that's how I see it. (Meeting 5)*

According to the co-researchers, these restrictions not only have negative consequences on their freedom, but also contribute to people with intellectual disabilities being singled out and stigmatized against by their communities.

Jordi: *Now they talk about us behind our backs, because we go everywhere with a monitor. Before they would stop you on the street and talk to you, but now they look at us badly because we are accompanied. (Meeting 5)*

Rosa: *Sometimes people say "look, she is stupid..." (for going in a group with a monitor). Not before, but now they look at us on the street. (Meeting 5)*

4. Discussion

The situation arising from the COVID-19 pandemic has imposed restrictions on society as a whole in relation to physical encounters, and has required the use of technical resources for communication that have had a significant impact on people's lives. In this context, people with intellectual disabilities have seen their opportunities to meet, organize, debate and report violations of their rights restricted. The objective of this study was to explore the impact that the pandemic had on the relationships of people with intellectual disabilities and to provide information on how this inclusive research was developed. According to Amor et al. (2021), it is necessary to listen to the voice of people with intellectual disabilities so that they express their needs and experiences regarding the COVID-19 pandemic.

One of the main findings of this study is the impact that the pandemic has had on the way of maintaining contact with other people. The participants of this study highlighted the need they had to use digital tools to be able to communicate with their friends and family during confinement. Although they valued their learning very positively, the use of technology did not represent a relationship opportunity for all people with intellectual disabilities, since not all had the necessary technological material or support to use it. In addition, the participants also pointed out that, although they were able to maintain contact with some people online, this contact was cold and dehumanized. Seeing friends and loved ones in person, or hugging and kissing them, are some of the things they missed the most. For most participants, physical contact is essential for relationships.

Another result that should be noted in this study is the social isolation that the participants in this study reported having suffered from not being able to see friends, partners, and/or some relatives, coinciding with the results of the research by Embregts et al. (2020) and McCarron et al. (2020). Additionally, in Amor et al. (2021), participants reported missing someone during the lockdown. In addition, the participants of this study also reported the loss of their work, occupational or training activity as another aspect that greatly affected them. This coincides with the accounts of those interviewed by Embregts et al. (2020) and those surveyed by McCarron et al. (2020) and Amor et al. (2021).

One of the significant effects of the pandemic has undoubtedly been on the mental health of the population. More than half of the participants in research undertaken by McCarron et al. (2020) and Drum et al. (2020) experienced anxiety or depression due to the

pandemic and its restrictions and, as Drum and colleagues pointed out, these emotional problems could continue to increase. In our study, emotional or mental health problems were not directly mentioned, however, the participants expressed their unhappiness at the fact that, almost two years after the onset of the pandemic, people with intellectual disabilities who live in group homes continued to have both relational and social restrictions, in addition to restrictions with mobility and social participation, in their day to day lives, despite the fact that the administrations already made measures more flexible for the population as a whole. A displeasure that is strictly related to a significant setback in the exercise of their basic rights, such as the right to mobility, assembly or independent living. Furthermore, it has been demonstrated that isolation and loneliness can be related to depression (Aanes et al. 2010), while, on the contrary, participation in society is related to low levels of depression, stress or anxiety (Ward et al. 2013). These data are relevant if it is taken into account that people with intellectual disabilities constitute a group with a high prevalence of mental health disorders, which is why they may present a greater need for help and/or support than the general population (Amor et al. 2021).

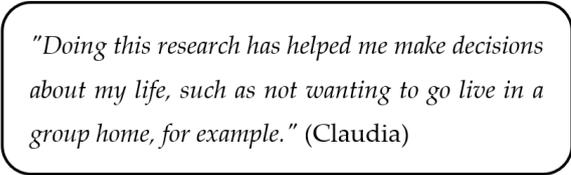
In Spain, research on the effects of the pandemic and confinement on the lives of people with intellectual disabilities has been very limited compared to existing international studies (Amor et al. 2021). Furthermore, no Spanish studies were found that analyse the effects of the pandemic from the perspective of people with intellectual disabilities themselves. As stated by Amor et al. (2021), the lack of research in this regard is worrying, since Spain was one of the countries most affected by COVID-19 in 2020. In addition, specifically the impact that the pandemic has had on the relationships of people with intellectual disabilities has been very little studied, unlike its impact on labour inclusion, access to education, health, or information, among others. Additionally, although the emotional impact of the pandemic has been studied, its influence on social isolation, loneliness, loss of friends, and difficulties in maintaining relationships encountered by people with intellectual disabilities has hardly been analysed. This is especially worrying considering that, as previous literature warned, people with intellectual disabilities tend to experience greater social isolation as well as significant barriers to establishing and maintaining satisfactory social relationships (Gilmore and Cuskelly 2014; Callus 2017). According to Duggan and Linehan (2013), some of these barriers are due not only to the lack of natural supports (family, friends, or neighbours) or the difficulty of making friendships, but also to the lack of involvement of service professionals in supporting people with intellectual disabilities to improve their social networks. In this regard, Sullivan et al. (2015) point out that the attitudes of professionals and their overprotective behaviour towards people with intellectual disabilities must be considered. They also emphasize the importance of professionals being aware of the extent to which the organization can limit or facilitate the opportunities of people with intellectual disabilities to establish satisfactory social relationships. These results and those of our research could indicate that the pandemic could have worsened a long-standing issue: the lack of support that people with intellectual disabilities experience to establish and maintain valuable relationships and participate in their communities.

This study makes an addition to the limited research that explores the perception of people with intellectual disabilities regarding the effects and consequences that the pandemic has had on their lives. It is relevant to consider the impact of COVID-19 on the relationships of people with intellectual disabilities if we take into account that the participants mentioned that friends were a valuable source of support, both to overcome complicated situations and to promote and maintain good emotional health. In this sense, the results of this research show that some people with intellectual disabilities continue to experience difficulties in overcoming the social isolation that the pandemic has caused in many cases, either due to lack of access to technologies that facilitate communication and/or the lack of support to use them, or because of the strict restrictive measures that are being applied to people with intellectual disabilities who live in residential institutions, such as group homes. In all these cases, there is a patent lack of support that should respond better

to the needs of people with intellectual disabilities and that would guarantee the exercise of their rights, especially in times of pandemic. Following on in this line of argument, we consider that it is an urgent matter to investigate the situation experienced by people with intellectual disabilities who are institutionalized, in group homes and residences (Verdugo et al. 2009; Huete et al. 2015; Puyaltó and Pallisera 2018), and specify what type of support is necessary to avoid their isolation and guarantee their rights, in a context in which the risk of contagion is imposed on their routines. According to the European Commission (2009), institutionalization refers to any residential care where: “users are isolated from the broader community and/or compelled to live together; these users do not have sufficient control over their lives and over decisions which affect them; and the requirements of the organisation itself tend to take precedence over the users’ individualised need” (p. 9).

This research was promoted by co-researchers with intellectual disabilities with the support of researchers. The impossibility of holding meetings in person during the development of the research forced all participants to adopt an online work format. The online situation led the research team to explore new ways of working, such as dividing into small simultaneous work groups or using WhatsApp to conduct interviews, among others, which were positively valued by co-researchers. These strategies coincide with those proposed by Miller and Heumen (2021) to successfully conduct inclusive research online. They highlighted the importance of using online platforms with which the co-researchers are familiar, offering them support in the use these platforms, adapting the format and timing of the meetings, or using accessible data collection strategies, as was performed in this study. Even so, it is necessary to remember that, in our study, all the co-researchers had access to the technology and received support regarding to use it, so the barriers they encountered to participate in the study were minimal.

In relation to the subject of this research, the co-researchers emphasized the importance of personal relationships and the seriousness of social isolation; a feeling of loneliness that some of the co-researchers claimed to have felt. Co-researchers also reported that the restrictions imposed during the toughest times of the pandemic are still in force for many of them, especially those who reside in institutions, and that it is necessary to report the rights they have lost, such as being able to go alone to different places, being able to choose which leisure activities to carry out during their day to day lives, or going to friends’ houses to eat, among others. In any case, they considered that participating in this research has allowed them to better understand the situation they are experiencing and, in some cases, make decisions about their lives based on the knowledge acquired (Figure 5).



“Doing this research has helped me make decisions about my life, such as not wanting to go live in a group home, for example.” (Claudia)

Figure 5. Co-researcher’s opinion 10.

Some co-researchers valued this inclusive research experience as an opportunity to make their role as researchers and the situations that people with intellectual disabilities have experienced during the pandemic known to society (Figure 6). In general, the entire team agreed that inclusive research has had an impact that goes beyond traditional research. Not only it allows us to share experiences and opinions between academics, non-academics and people of different ages and backgrounds, and learn from each other, but also to socialize and feel understood during a difficult time such as a pandemic.

"(Spreading awareness of this research) is important for people to see that we can conduct research, and also for them to see how we lived during the pandemic." (Rosa)

Figure 6. Co-researcher's opinion 11.

Finally, the co-researchers expressed the desire and willingness to continue conducting research (Figure 7). Some of the topics that interest them are community participation and the freedoms they possess and/or do not possess. They are aware that, as far as possible, conducting the research in person would be more suitable, since it would allow them to see each other, communicate and understand each other better.

"With the experience we now have, if we conduct further research, it will surely turn out better, because the more times you do things, the better they turn out." (Jordi)

Figure 7. Co-researcher's opinion 12.

The research carried out has some limitations. First, the small number of people who participated in the interviews and focus groups. Altogether, there were 37 people, a small sample of people with intellectual disabilities. In addition, the sample does not include people with greater support needs, so the consequences of the pandemic in the personal relationships of this sector of the population have not been addressed by this research. Despite these limitations, we wish to point out that the aim of this inclusive research did not seek to generalize the results. It started from an interest of the advisory committee itself and contributed to the participants exploring their situation and that of other people with intellectual disabilities, becoming aware of the consequences of the pandemic on their social relationships. The process aroused their interest in disseminating the results, as a result of which the article presented has been written.

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