ORIGINAL ARTICLE



The importance of social relationships and loneliness: An inclusive research project in Spain

Susana Rojas-Pernia | Ignacio Haya-Salmón | Santiago Lastra-Cagigas | Lucia Álvarez-Sáenz de Santa María

Department of Education, University of Cantabria, Santander, Spain

Correspondence

Susana Rojas-Pernia, Department of Education, University of Cantabria, Avda. Los Castros, s/n, 39005 Santander, Cantabria, Spain. Email: rojass@unican.es

Funding information

This work was supported by the Ministry of the Economy and Competitiveness (EDU2015-68617-C4-4-R). Principal researcher: Teresa Susinos Rada

Accessible summary

- This article presents part of the research project we carried out on the importance of social relationships and loneliness in young people with and without intellectual disabilities.
- We interviewed 23 young people during our research which was developed over more than a year and a half.
- Social relationships are important for young people both with and without learning disabilities. A person may want or need to be alone, but nobody wants to feel lonely.
- We wrote this article collaboratively. People with a intellectual disabilities do not often contribute to written papers.

Abstract: This article presents the results of a project carried out by a group of researchers with and without intellectual disabilities on the importance of social relationships and loneliness. We wanted to find out about the experience of loneliness in young people with and without intellectual disabilities and know whether this was an important issue for them too. We interviewed a total of 23 young people during our research which was developed over more than a year and a half. This article has been organised into three parts. In the first part, the two academic researchers outline the concept of inclusive research highlighting the value of recognising and making the experiences of people with intellectual disabilities visible. Following this, the four authors describe how the research group was formed and the methodological decisions that were made. Finally, we report the results of the research and the main conclusions. The young people with and without disabilities we interviewed told us that nobody wants to feel lonely. We believe that it is important for other researchers at the university to recognise our work and be encouraged to implement inclusive research processes.

Research group Inclusionlab Project

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2020 John Wiley & Sons Ltd



KEYWORDS

inclusive research, learning (intellectual) disability, relationships and loneliness

1 | BACKGROUND

1.1 | Inclusive research

The term inclusive research comprises a set of approaches and methods that are described differently in the literature. These approaches emphasise the democratisation of collaborative inquiry processes and, consequently, the type of relationships that can be established between participants from academic and non-academic sectors (Nind, 2014, 2017).

Specifically, the term inclusive research is used to refer to a methodological approach that "consider people with learning disabilities as more than just subjects of research. They are actors, whose views are directly represented in the published findings in their own words" (Walmsley & Johnson, 2003, pp. 61–62).

A recent systematic review of inclusive research defines it as:

- "Research that aims to contribute to social change, that helps to create a society in which excluded groups belong, and which aims to improve the quality of their lives.
- Research based on issues important to a group and which draws on their experiences to inform the research process and outcomes.
- Research which aims to recognise, foster, and communicate the contributions people with intellectual disabilities can make.
- Research that provides information which can be used by people with intellectual disabilities to campaign for change on behalf of others.
- Research in which those involved in it are 'standing with' those whose issues are being explored or investigated" (Walmsley, Strnadová, & Johnson, 2018, p. 758).

The academic researchers would like to draw particular attention to two of the principles mentioned previously. Firstly, inclusive research recognises the experience of people with intellectual disabilities and with this knowledge highlights the complexity that surrounds the life of any person. This means valuing and placing the main focus on the co-researchers and their life experiences. We all have a biography and our biographies are built with people and the situations we have lived, something which invites us to listen to others and know the ways in which they have made this knowledge their own (Rojas-Pernia, & Haya-Salmón, 2020). On the one hand, common experiences become visible, some of which involve the conditions of disability and, on the other hand, other forms of expressing, communicating and sharing what is important personally and socially.

Undoubtedly, inclusive research is the path which allows academic researchers to know, consider and address topics or issues with co-researchers which they would not otherwise have contemplated or been able to answer. It also enables co-researchers

to look in depth, with other researchers, at issues that not only affect them but also other people with and without disabilities. For both groups, the research space can be a shared space from which to begin and research together on social issues relevant to people with intellectual disabilities (Walmsley et al., 2018). In this context, the academic researchers put their skills and resources at the service of the research, aware that these are insufficient when the research contemplates the plurality of situations in which people with intellectual disabilities find themselves (Milner & Frawley, 2019; Nind, 2014). Throughout the whole process, it is necessary to pay attention to the way in which we relate to each other, the development of listening or how we incorporate the proposals from all members of the group (Purcal, Fisher, Robinson, Meltzer, & Bevan, 2019). Obviously, listening within the team is an essential condition required for transcending methodological limits and pedagogical certainties.

The second issue we want to highlight is the contribution of research to social change. Inclusive research can improve the living conditions of people with intellectual disabilities and their families. It recognises them as experts and agents capable of influencing the contexts in which they live, which impacts the way people with intellectual disabilities represent themselves and the importance of their actions and decisions (Nind, 2014; Walmsley & Johnson, 2003).

Likewise, the review of the practices of collaborative research with people with intellectual disabilities (Bigby, Frawley, & Ramcharan, 2014) has broader effects. Firstly, it affects academia and the ways in which research is carried out. According to Milner and Frawley (2019), researching from an inclusive paradigm requires academics to think about what is done and whether this changes discourses or continues repeating schemes that subjugate people with intellectual disabilities. Recognising them as co-researchers implies listening, knowing, negotiating, arguing, addressing and finding new ways to be together. The documentation, analysis and dissemination of research processes and results need to identify the limitations that emerge from particular projects and the restrictions that other forms of exclusive research impose on the co-production of knowledge (Bigby et al., 2014; Ellis, 2018; Fudge, Wilton, & Marquis, 2019).

Finally, it is impossible not to consider the implications that the above has for all citizens. Inclusive research empowers people with intellectual disabilities and therefore also modifies the dominant deficient representation of this group over centuries. It transforms the types of relationships we establish and the ways in which we do this. The recognition of people with intellectual disabilities forces us to reflect on political decisions that are made and question what we believe we know. It encourages us to think about the type of society we want, something which also affects everyone.

1.2 | Loneliness and people with learning disabilities

Some recent studies highlight the lack of work on loneliness in people with learning disabilities and the need to expand current research (Gilmore & Cuskelly, 2014; Mooney, Rafique, & Tilly, 2019; Petroutsou, Hassiotis, & Afia, 2018; Tilly, 2019). According to these authors, loneliness can be defined as a painful experience that appears when there is a discrepancy between a person's expectations with respect to relationships and their experience. In this regard, it is possible for a person to be surrounded by other people and yet feel that they are not important to those people and feel alone.

Although this is an important issue that affects the population in general, the review of research carried out by Gilmore and Cuskelly (2014) shows that the experience of loneliness is common for people with learning disabilities and affects adults to a greater extent. The authors refer to individual issues that could be conditioning the beginning and maintenance of social relationships such as the difficulties in communication and decision-making that some people have. However, this work highlights the role that attitudes and social expectations about people with learning disabilities play in loneliness or the lack of opportunities to access environments where friendships could be established.

As the research group "Building Bridges" (Mooney et al., 2019) suggests in a recent study, it is more difficult for people with learning disabilities to be involved in their communities and, therefore, changes in community meeting spaces are necessary. As the group states, "we have thought about what we think should change to enable more community inclusion and so help reduce feelings of isolation and loneliness" (p. 245).

1.3 | How this article was written?

This article was written by the two academics researchers together with two of the co-researchers with learning disabilities. To write it, the two academic co-researchers reviewed the field notes and video and audio recordings from each of the sessions as well as some of the other materials we prepared such as a poster of the whole project. This material helped us to structure the article and identify some of the important ideas. After this, the co-researchers interested in writing this article met to read, discuss and reflect on the written text. Considering that many of the people who read this article will be researchers without intellectual disabilities, the two academic researchers have written the first part of the article (background).

The purpose of the research was to find out about the experience of loneliness in other young people with and without intellectual disabilities and to know whether this was also an important issue for them. With this article, we want to present the main results of our research in which we interviewed 23 young people with and without disabilities.

2 | AN INCLUSIVE RESEARCH PROJECT IN SPAIN: THE IMPORTANCE OF SOCIAL RELATIONSHIPS AND LONELINESS

2.1 | Who are we?

The team consisted of ten researchers made up of eight young people with learning disabilities and two academics from the Faculty of Education (University of Cantabria). Some of us knew each other previously because we had worked together in self-advocate groups. The project, "The importance of social relations and loneliness," is the result of our work together. The two academic researchers contacted the social entity that runs the self-advocate programme and invited us to a meeting which was also attended by our families. In this meeting, we proposed creating a research group in which we could think together about important issues for people with intellectual disabilities. The research team was made up of all of those interested in the proposal.

We all received the research conditions in writing and had the opportunity to talk to our families and to each other during the first informative session at the university. The project was approved by the University of Cantabria Ethics and Social Sciences Committee in 2017.¹

When the project started, the eight co-researchers were aged between 19 and 26 years old. Although our educational trajectories had been different, all of us could read, write and use ICT to communicate. Some of the young people were in an Occupational Centre, two were looking for employment, and the rest were enrolled in some type of training programme aimed specifically at people with learning disabilities. This was our first research experience.

We began our research in February 2017 and finished it in July 2018. Following this, we continued working together to disseminate it using different media and formats. In addition to the web page,² we organised an exhibition at the university and prepared some press releases. We made some presentations (at conferences and during a subject on Educational Inclusion in the Research Master at the Faculty of Education). This is our first joint academic article.

This article contains the main results of the project on *the importance of social relationships and loneliness*. As Santiago, one of the co-researchers, points out, it is important that other people know "that people with learning disabilities also have social relationships and how they feel about loneliness" (Video Recording, 2019_nov). The loneliness that some people with learning disabilities experience occurs in close environments (family, friendships or work), and people need to know that people with learning disabilities do not choose to be lonely. It is an unjust, painful and difficult situation for those who experience it.

¹This work was supported by the Ministry of the Economy and Competitiveness. Researcher Coordinator: Teresa Susinos Rada.

²The website includes the whole research process (phases, strategies, personal reflections,...). https://inclusionlab.unican.es/plenainclusion/



In addition, this article aims to share with other researchers the experience we have developed. We think it is important that other university researchers recognise this work and are encouraged to implement inclusive research projects.

2.2 | What concerned us? Deciding on the research topic

The first meetings were a space to get to know each other, discover what it meant to form part of a research group and define the channels and means that we wanted to use to communicate. They also provided a space for us to discuss socially unjust situations that disturbed us. During the first five meetings, we addressed issues that worried us personally and socially.

In the first five meetings, we talked about unjust situations: rejection or isolation experienced at school, the fear of losing current friends and the discomfort arising from not having a partner, not having a job or the fear of losing our parents and brothers and sisters. After the small group discussion, two topics were important. Some of the co-researchers proposed a secret ballot for the choice of topic. One person proposed researching on both. Finally, academics suggested that everyone argued for their final choice. Except for Lucia, the research team chooses to inquire about social

relationships and loneliness. These were some of the points that we raised in the final phase of the decision-making process in relation to the subject of this research:

- Chemi (co-researcher): 'Me and loneliness. We are social beings and we need to be surrounded by people. If you notice, lonely people are bitter.
- Elena (co-researcher): 'Me and relationships...nobody likes being alone, everyone likes to be surrounded by people.
- Gerardo (co-researcher): I would like the [topic] of being alone, for being with more people, interacting with more people, I don't want to stay at home alone.
- Belén (co-researcher): Relationships! Meeting people, not being alone, having friends.
- Mónica (co-researcher): Relationships! Because if I end up with nobody I would be totally depressed.
- Ernesto (co-researcher): Well, relationships because I don't want to be alone.
- Santi (co-researcher): Relationships! For not being alone, I want to have a partner...
- Lucía (co-researcher): Work.
- Susana (academic researcher): Relationships, although I think the two subjects are important (in reference to having a job), I



FIGURE 1 The importance of social relationships and loneliness [Colour figure can be viewed at wileyonlinelibrary.com]

prefer relationships, because it's important for those of us here but also for a lot of other people.

Nacho (academic researcher): Between the two, I also go with relationships. I think it has been very present since we met. I think that although we haven't named it, it was one of our concerns.' (VR, 2017, April).

We organised all the ideas that had arisen on this subject in previous sessions, and we shaped them through the use of an image (Figure 1). This served as a starting point for deciding the general objective of the research, the participants and the data collection techniques.

2.3 | How was the research carried out?

This inclusive research project is situated within the qualitative research approach (Denzin & Lincoln, 2012). The research design takes shape as the research progresses and all those involved agree on appropriate decisions through a deliberative process, for example what the research topic is, what tools and techniques are the most suitable in order to achieve the research objectives or how to carry out data analysis.

The first meeting took place in February 2017. We met twice a month. We did a number of different activities using various techniques. For example, we used personal belongings, image theatre and photography as well as visual panels to aid the organisation of ideas and proposals. We recorded each of the sessions in audio and video, and we took photographs of the materials we produced and of the situations that seemed important to us. Sometimes, we used these materials in our work sessions.



FIGURE 2 Example group of statues in the playground. (Image created through image theatre) [Colour figure can be viewed at wileyonlinelibrary.com]

We wanted to know whether other young people with or without learning disabilities had ever felt alone, in which situations, and whether it was an important topic for them. The technique that allowed us to explore and inquire about personal experiences was the semi-structured interview, and together, we started to think about the questions. Some of us found this part of the process very difficult although the activities and materials mentioned previously (e.g., image theatre and photography) helped us (Figure 2).

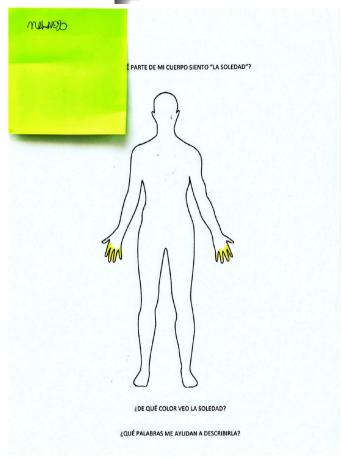
Once the interview had been designed, we decided to rehearse between ourselves and explore the difficulty of the questions or the importance of respecting the response time of the people who participate. We also talked about ethical issues in research, such as confidentiality, avoiding judging the participants and recognising their stories and opinions as valuable (Figure 3).

Finally, we decided to interview young people between 18 and 30 years old with and without learning disabilities. Using the snowball technique, all the members of the research team made proposals to people in their environment who met the age criteria. It was easier to have access to young people in the latter case. However, one of the co-researchers (Lucia) acted as "gatekeeper" and made it possible for us to interview some of the young people who attended the training centre (for people with learning disabilities) where she goes. Nobody was left out. All those who wanted to participate were included regardless of their abilities, but everyone was able to communicate verbally. Finally, we interviewed 23 young people with and without intellectual disabilities.

We did the first interviews in small groups at the Faculty of Education and then we did them in pairs, but always with the support of one of the academic co-researchers. The first two interviews with young people with learning disabilities helped us realise that some questions were difficult to answer and the participants did not specify situations they had experienced or the obstacles they encountered. They also helped us find out that we explored situations in which the young people had felt part of a group or had felt that they were important to other people. We met and decided that we needed to find another way to get



FIGURE 3 Interview training [Colour figure can be viewed at wileyonlinelibrary.com]



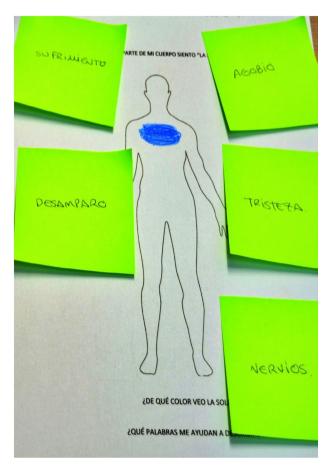


FIGURE 4 Two Body Map examples (Example 1. "I feel the loneliness in my hands"/Example 2. "When I feel alone, I feel helpless, suffering, overwhelmed, sad and nervous" [Colour figure can be viewed at wileyonlinelibrary.com]

more information about what concerned us, and the two academic co-researchers proposed introducing body mapping. As some authors state (Lyon, 2020; Mannay, 2016), it is possible to use drawing for in-depth inquiry into individual perceptions and experiences. We also decided to include speaking activities to elucidate the finished drawings, ensuring the participants' meaning is the main focus of the analysis.

Again, we wanted to try out what it involved and what the participants would have to answer. We realised that the mapping "provided twice as much information" (Santi), helped more people to participate (Gerardo) and "it was easier to research and analyse the results" (Santi), although "some things were more difficult" emotionally (Elena).

To analyse all the data, we obtained we proceeded in the following way:

- The academic researchers were responsible for transcribing the interviews. Reading all the texts with the transcriptions was difficult for most of the group. Therefore, we dedicated two sessions to analysing the interviews and the fragments that had been previously selected by the academic researchers.
- The fragments that we analysed helped us to discuss, think and try to identify the subjects that had emerged from the interviews.

The whole team was able to work with some interview fragments
with the aim of highlighting: what the people we interviewed
talked about, what they thought about social relationships and
loneliness, how they valued these questions, what ideas were repeated or are more common, and what it makes the researchers
think about.

2.4 | What did the participants in the research tell us?

2.4.1 | Relationships with other people are important: "Loneliness is an unpleasant feeling" (Leire, 21 years old)³

Relationships with other people are important for the 23 participants. We need to share with other people, relatives or friends what happens to us and participate in spaces and activities that are important or valuable to us. When we can do it, we feel good, we feel recognised and valued by other people. In the words of some of the

³In total, 23 young people participated in the research. Leire, Sonia, Anjana, Francisco, Carmen and Lorena are young people without learning disabilities. Samuel, Elisa, Adolfo, Lourdes and Antonio are young people with learning disabilities.

young people "I need to be with people. I like to interact and be with people who satisfy me and have relationships with normal people" (Samuel, 26 years old).

I like to interact with people that I have known a long time and with new people. I am always aiming at things, doing things to interact with people because I like them a lot and I think they are very important.

(Sonia, 20 years old)

(it makes me feel good in social relationships) '...feel valued, feel that that person wants to hear from you, that they ask how your day was, those things well it means more than anything to feel that that person wants to be with you.'

(Anjana, 18 years old)

When we ask whether it is the same to be alone as feel alone, most young people respond that some people may need time on their own, to disconnect from external demands or to think about important issues.

Loneliness is not being alone...you can be alone and feel ok...loneliness is a state in which you are alone but don't want to be.

(Anjana, 18 years old)

Therefore, being alone can be a chosen situation that makes you feel good. But being alone is not the same as feeling lonely. Loneliness or feeling lonely is the result of an imposed or forced situation that generates suffering.

Feeling lonely is not having friends, not going out, like staying at home marginalised. Loneliness is feeling lonely, I think (...) Feeling lonely is not having anyone and being alone is, for example, when your parents have gone out to do an errand, but they come back. That is not feeling lonely that is being alone.

(Elisa, 19 years old)

Except for three young people with learning disabilities who explained that they have never felt lonely, everyone else shared situations with us in which they had felt, sad, helplessness, fear, nervousness, incomprehension, pain, insecurity and shame (Figure 4).

To sum up, they express feelings and negative emotions that cause pain in the people interviewed:

Loneliness is a bad thought, a bad emotion, when sadness or fear – or things like that – overcome you.

(Francisco, 21 years old)

When you don't feel connected to anyone or anything. You might be with people, but you don't feel connected, you don't feel supported or secure.

(Anjana, 18 years old)

In addition, as stated in the previous example, loneliness is the result or consequence of what other people did, whether it is an action or omission, provoking situations or experiences of isolation, confinement or exclusion. Body mapping made it possible for all the young people to share an experience in which they had felt lonely and how they had embodied that feeling. It also meant that those who had never experienced it could imagine what that situation would mean to them.

2.4.2 | 'The feeling of loneliness leads you to believe that you don't have anyone: no family, no friends, nobody' (Carmen, 27 years old)

The majority of young people with and without learning disabilities felt lonely at some point in their lives. For example, Francisco's family relocated to another city for work, and this triggered feelings of isolation which not only increased at school but also at home,

When we went to Madrid we had a lot of problems at home. The situation was terrifying. School saved me. Despite this, there were days when everything got me down and I cried because I couldn't cope, then, the school didn't support me, but I interpreted many situations that weren't real. Maybe it was because of the type of communication. But of course when the school became a prison and home another one and I wasn't old enough to go out and my parents were strict about that, I felt lonely.

(Francisco, 21 years old)

However, most of the situations of loneliness that the participants shared with us took place at secondary school. Many of them remember moments when they felt out of place, when they did not know who to talk to or who to tell what was happening to them or who they could share an activity with. As the young people with and without disabilities said, secondary school was not a good place for some people:

I didn't have many friends either. There was a time when I was alone, I hardly interacted with anyone and I had to study and it was quite a long process. (...) alone in class, alone at home and alone in the street.

(Samuel, 26 years old)

"Well during break time in the last school which was in Secondary Education. I tried to join the group but nobody liked me. And I felt lonely. I said to myself: and me, who can I talk to? I felt lonely having no friends. I tried to join groups of girls. But they ignored me and didn't want to be with me, and I wondered why? If I'm like them" (Elisa, 20 years old). The absence of interaction, lack of communication or indifference by peers appears to explain the isolation suffered by Francisco or Samuel. In contrast, for other people, rejection by their classmates was more obvious and damaging as explained by Elisa, Adolfo or Lucia. These young people talk about behaviour that signified continuous rejection or physical or verbal abuse which led some of the interviewees to confine themselves at home.

(...) when I was bullied for example. There wasn't even one classmate who helped me. They insulted me, treated me like a child...spat at me. That was from the first year of secondary school to the 4th. (...) No, nobody helped me. I couldn't defend myself because I was younger (...) I wasn't able to defend myself then, now I can and I would report them to the school.

(Adolfo, 23 years old)

When I changed from 4th year of Secondary Education to baccalaureate, my classmates were put in other classes and I didn't coincide with them and then I felt lonely. Afterwards, in this class I was bullied, so my feeling of loneliness became even more intense.

(Lorena, 29 years old)

We also found other situations in which the feeling of loneliness was generated by a bad relationship ("a couple relationship which I had to leave and which I couldn't leave because I didn't have any help, nobody to ask for help and I didn't know how to do it", Olga, 24 years old) or the fear of not knowing where your parents are going or what they are doing (Lourdes, 25 years old).

Likewise, friends and some people from the family environment reappear when people who listen to them, accompany and support them and enable them to move forward are mentioned.

2.4.3 | Some devices—such as smartphones—do not allow us to realise "what's happening around us" (Antonio, 26 years old)

We also asked about objects or attitudes that lead to some people being alone and feeling lonely. In both cases, the responses mostly coincide. In other words, when we talk about objects, the use of mobiles is the obstacle that is repeated the most. Although it facilitates closer and more permanent communication, it is "what prevents you from communicating to the person next to you" (Sonia, 20 years old). It is common to see people in the same physical space chatting on their mobile. It appears that they do not notice that other people are physically there. In the words of Adolfo, it is possible to see groups

of people, for example relatives, who hardly speak to each other: "People hide away and do some unbelievable things. For example, maybe you're with a phone and the father and son are there and they don't even look at each other, because there's no relationship." (Adolfo, 23 years old).

The moment we talk about attitudes there are two types of responses. Firstly, indifference towards other people and what happens to them. The interviewees highlight that the origin or cause of this indifference is being in a rush, our tendency to make rapid judgements of other people or selfishness. In the words of Anjana:

There are many people who ridicule others. They aren't aware of it, but they make people feel that they aren't part of the group (...). Lack of respect, no empathy, they make comments about a situation someone is experiencing with attitudes that make that person keep a distance. (...)it is education and reflection, about what we say and why we say it.

(18 years old)

Secondly, the conscious and intentional attitude of generating pain in other people, sometimes through language. In Sonia's words, the problem is with people who drag other people so that others are left alone:

Yes, attitudes, I don't like saying that a person is bad, but they take others with them, they drag the rest and can leave someone alone in a group, in a class, at work; someone who is the ringleader (...) and they drag the entire group and can leave the other person on their own.

(Sonia, 20 years old)

2.4.4 | Social changes are necessary: "it is necessary to be very attentive to others so that nobody is left alone."

Some of the young people believe that if everybody experienced loneliness at some point in their lives, we would be more careful with our attitudes or actions towards others. For them, this would avoid bullying or the indifference with which we respond to the social isolation that some people experience.

However, for many young people nobody should feel lonely at primary or secondary school because everyone should have the opportunity to be respected or know that they are recognised. Consequently, when we ask the young people what they would change about their experiences, they state that they were not the problem and therefore they would change the people around them: "(...) I didn't do anything to make them treat me badly. I'd change them for people who valued me and treated me well (...) they tried to annoy me, they threw paper at me, I wish they wouldn't touch me physically or laugh at me for no reason...once they closed the door

and they hit me...I wish it wasn't like that for me or for anyone else" (Lorena, 29 years old).

This is a very complex issue for some people involved in education at different levels. For Francisco (21 years old), the key is in the social values that are prioritised and valued by the school:

They educate us in competitiveness, they generate very different interests, and that leads to groups of people being alone. If we were educated in cooperation instead of competitiveness and in equality instead of inequality, I think that there would be problems, many personal relationship problems that would be resolved.

(Francisco, 21 years old)

In that context, it is possible to imagine the change that other young people propose. As highlighted by Sandra (20 years old), it is necessary "to be very attentive to others so that nobody is left alone." This means we need to listen and observe around us, because although it is important to ask for help from other people and explain to them how we feel (Lorena, 29 years old), some people feel that they are unable to do this.

Some of the interviewees suggest that structural changes are necessary. Loneliness is not an individual phenomenon, but the consequence is that some people experience in different environments that they do not feel part or feel that they are less valued. As Adolfo suggests, "schools should support people more and try to prevent anyone from harming anyone else. (...) because what they did to me was to separate me, but that's not help. Why should I be separated from those people? Although they hurt me. Why should I separate myself from those people? Although it hurts. I wouldn't choose to be with those people, but I don't have to leave a place if they are there, I think they should go" (23 years old). For this young man, the solution is not to separate the person who is suffering harassment or who is not accepted by others, because this reinforces the behaviour of these people. His reflection also leads us to think about the messages that are given to those who are passive spectators of these situations.

2.5 | What did we learn?

This research gave us the opportunity to know what it means to research a topic that concerns us and matters to us. In addition, it has allowed us to tell other people (relatives, friends, professionals...) what we have done and how we have developed it. Some of the main conclusions of this work are listed below:

- We can be surrounded by people, but feel alone.
- When nobody pays attention to you, you feel that you are not important and loneliness grows.
- Perhaps there are some moments when we like or need to be alone to dedicate time to ourselves, but when others make us

- feel lonely, this generates discomfort and makes us feel bad. Loneliness also invades our thoughts and ideas.
- The people we have interviewed want to feel part of "something": a group or an activity.
- We are aware that people feel, live and experience loneliness in different ways. But also that people with and without disabilities feel, live and experience it. Most of us have experienced loneliness
- It is important that everyone is taught to respect, welcome and treat others well.

Based on the learning gained in the research process, we think it is important to contribute to identifying or intervening in situations of loneliness or isolation in our environments (family, work or school). Thus, for example, we could design future practices that allow us to apply what has been learnt to the environments in which we participate. Finally, in this work we have identified some limitations that we think it appropriate to share. In our first jointly written article, we decided to allocate more space for the presentation of the results and learning linked to the topic that concerns us: social relationships and loneliness. At the moment, we believe it is more relevant to share an important idea: young people with and without intellectual disabilities worry that the way we interact with other people means that some of us are exposed to situations of rejection, exclusion or imposed loneliness. It is important to make some of the learning derived from this project visible so that other people can know situations that, for some people, are unjust and painful. In our opinion, this adds value to our work and contributes to transforming the reality that surrounds us, principally the way in which processes of exclusion, isolation or imposed loneliness are constructed. Therefore, we have paid less attention to explaining the entire research process and the different phases we developed or the techniques or tools used for data collection. Aware of this, the description and reflection on how we have researched collaboratively will be addressed in future articles so that other researchers can know our work and help us improve in this complex, but exciting, task of investigating what is important to us.

ACKNOWLEDGEMENTS

We thank all the young people who supported the project selflessly.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Susana Rojas-Pernia https://orcid.org/0000-0002-4617-241X Ignacio Haya-Salmón https://orcid.org/0000-0003-1391-3311

REFERENCES

Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of*

- Applied Research in Intellectual Disabilities, 27(1), 3–12. https://doi.org/10.1111/jar.12083
- Denzin, N., & Lincoln, Y. (2012). Manual de investigación cualitativa. Barcelona, Spain: Gedisa.
- Ellis, L. (2018). Making decisions together? Exploring the decision-making process in an inclusive research project. *Disability & Society*, *33*(3), 454–475. https://doi.org/10.1080/09687599.2017.1392932
- Fudge, A., Wilton, R., & Marquis, N. (2019). Building collaboration in the co-production of knowledge with people with intellectual disabilities about their everyday use of city space. Area, 51(3), 415–422. https://doi.org/10.1111/area.12492
- Gilmore, L., & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: An explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 192–199. https://doi.org/10.1111/jppi.12089
- Lyon, P. (2020). Using drawing in visual research: Materializing the invisible. In L. Pauwels & D. Mannay (Eds.), *The Sage handbook of visual research methods* (2nd ed., pp. 297–308). London, UK: Sage.
- Mannay, D. (2016). Visual, narrative and creative research methods. New York, NY: Routledge.
- Milner, P., & Frawley, P. (2019). From 'on' to 'by': People with learning disability creating a space for the third wave of inclusive research. Qualitative Research, 19(4), 382–398. https://doi.org/10.1177/1468794118781385
- Mooney, F., Rafique, N., & Tilly, L. (2019). Getting involved in the community—What stops us? Findings from an inclusive research project. British Journal of Learning Disabilities, 47, 241–246. https://doi.org/10.1111/bld.12283
- Nind, M. (2014). What is inclusive research? London, UK: Bloomsbury.
- Nind, M. (2017). The practical wisdom of inclusive research. *Qualitative Research*, 17(3), 278–288. https://doi.org/10.1177/1468794117 708123
- Petroutsou, A., Hassiotis, A., & Afia, A. (2018). Loneliness in people with intellectual and developmental disorders across the lifespan:

- A systematic review of prevalence and interventions. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 643–658. https://doi.org/10.1111/jar.12432
- Purcal, C., Fisher, K., Robinson, S., Meltzer, A., & Bevan, N. (2019). Coproduction in peer support group research with disabled people. *Area*, 51(3), 405-414. https://doi.org/10.1111/area.12441
- Rojas-Pernia, S., & Haya-Salmón, I. (2020). Inclusive research, learning disabilities, and inquiry and reflection as training tools: a study on experiences from Spain. *Disability & Society*. [The data of authorship and title of the article have been deleted to guarantee the anonymity]. https://doi.org/10.1080/09687599.2020.1779038
- Tilly, L. (2019). Experiences of loneliness: People with a learning disability and barriers to community inclusion. In B. Fox (Ed.), *Emotions and loneliness in a networked society* (pp. 201–221). Wolverhampton, UK: Palgrave Macmillan.
- Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities. Past, Present and Futures.* London, UK: Jessica Kingsley Publishers.
- Walmsley, J., Strnadová, I., & Johnson, K. (2018). The added value of inclusive research. *Journal of Applied Research in Intellectual Disability*, 31, 751–759. https://doi.org/10.1111/jar.12431

How to cite this article: Rojas-Pernia S, Haya-Salmón I, Lastra-Cagigas S, Álvarez-Sáenz de Santa María L. The importance of social relationships and loneliness: An inclusive research project in Spain. *Br J Learn Disabil.* 2020;48:291–300. https://doi.org/10.1111/bld.12342