

Community responses to LGBT+ adults with intellectual and developmental disabilities during the COVID-19 confinement in Madrid

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Abstract

A group of 50 people with intellectual and developmental disabilities (IDDs) as well as diverse sexualities and gender identities in Madrid participated in a feminist community-based project, which supported them through the first wave of the pandemic. Facilitated by professionals, the project offered online meetings twice a month, helping them to articulate their needs and promote their agency over their choices and experiences. Based on their demands, participants chose the topics they wanted to discuss, proposed activities, and were the center of the program, while facilitators set up and maintained the online space, helping with participation and access to information and resources. Through this transformative experience, the members of the group developed friendship networks and started their activism, making public appearances in video campaigns and mainstream newspapers to make their needs visible to peers, families, social workers, policy makers, and nongovernmental organizations (NGOs). This research is part of a larger project that tackles the psychosocial factors that affected Spanish people with sexual and gender diversity during the first wave of the pandemic.

Keywords

Agency, COVID-19, developmental disability, intellectual disability, LGBT+, lockdown

Introduction

One year after the first wave of the COVID-19 pandemic, Spain continues to be one of the top 10 places in number of deaths per 100,000 inhabitants (Johns Hopkins University, 2021). Spain started to face this crisis as it was beginning to emerge from the 2008 economic crisis; thus, this situation is generating large social fractures and vulnerability in some populations, such as people

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with disabilities (Amor et al., 2021; Courtenay and Perera, 2020). In this context, the lack of public policies for people with disabilities worsens their quality of life, making them four times more likely to have serious injuries than people without disabilities (Izutsu, 2019), which, in some cases, have even led to death (Chen, 2020). Indeed, in other disaster contexts, people with disabilities have been disproportionately affected by the failure to have their needs considered (Powell and Gilbert, 2006). These necropolitics (Mbembe, 2008) have serious consequences among a population already suffering from unfavorable situations and lead to an increase in such conditions (Kadir et al., 2019). According to the World Health Organization (WHO, 2015), of the 1 billion people with disabilities, 200 experience particular difficulties to survive.

Disability, disease, and age mark bodies and limit their access to livable lives (Moscoso and Platero, 2019), something that has become evident in the premature deaths of the elderly in Spain with the first wave of the pandemic, which amount to 93% of the death total (Government of Spain, 2020a). Many people with disabilities suffer unemployment in greater proportion, find themselves in situations of poverty, have more mobility difficulties, and fewer possibilities of autonomy (Institute on Disability, 2019; WHO, 2011). For people with intellectual and developmental disabilities (IDDs), the time of confinement and mobility restrictions during the first COVID-19 wave in Spain has meant giving continuity to previous semi-confinement experiences, when they already had few opportunities for agency and control over their lives (Navas et al., 2020; Verdugo and Navas, 2017). Difficulties accessing appropriate medical care have increased (Drum et al., 2020; Haverkamp et al., 2004), and their psychosocial health has worsened, with high levels of anxiety, behavioral problems, and regression in acquired skills, among other symptoms (Amor et al., 2021; Navas et al., 2020). According to Silván and Quíñez (2020), in Spain, people with IDDs have had a higher prevalence of COVID-19, due to preexisting conditions – respiratory disorders, hypertension, and immunosuppression – and also because they have had their health treatments interrupted due to the pandemic crisis response.

Social services in Spain have been overwhelmed, trying to cope with the many urgent calls for support, which has led to nongovernmental organizations (NGOs) and community networks to step in and coordinate a response to some people's most pressing needs (Federación Estatal de Lesbianas, Gays, Transexuales y Bisexuales [FELGTB], 2020; Plena Inclusión, 2021). Although most research has focused primarily on health professionals, social workers (along with other professionals working in social services and NGOs) have been absolutely indispensable during the response to COVID-19 crisis in Spain, covering the most urgent social needs of vulnerable groups (Redondo-Sama et al., 2020). These frontline social workers have faced a context of uncertainty with various barriers, such as a lack of personal protective equipment, an exponential increase in basic demands (housing, food, etc.), the temporary closure of other public services, lack of training or clear protocols for working amid the circumstances of COVID-19, as well as the ongoing changes in the official guidelines on COVID-19, among other obstacles (Farkas and Romaniuk, 2020; Redondo-Sama et al., 2020). As the International Federation of Social Workers (IFSW, 2020) stated, strengthening of health and social services is a crucial form of protection against the virus, fighting inequality and the social and economic challenges.

During the first wave in Spain, the social regulations concerning compliance with the confinement and movement restriction measures have singled out people with IDD, inviting them to use distinctive bracelets to avoid aggressions while outdoors (Government of Spain, 2020b). The discrimination people with IDD already faced (Dickinson and Yates, 2020, 4), especially if they have diverse sexualities and gender identities (Döring, 2020), has made them an often-invisible 'at-risk' group since the start of the pandemic and Spanish confinement restrictions.

In these circumstances, it is urgent 'to give people with IDD a voice to express their needs and experiences with respect to the pandemic' (Amor et al., 2021), and we must listen to them

accordingly and guarantee the exercise of their rights. It is here where the job of social workers has gained great relevance by ensuring that most vulnerable populations are included in the response (IFSW, 2020), and articulating solidarity networks that have allowed communication and the breaking down of physical boundaries with different vulnerable groups (Miller and Lee, 2020; Redondo-Sama et al., 2020).

This brief note presents the experiences of a group of LGBT+ people with IDD in Madrid who demand a space of their own and their right to participate in mainstream LGBT+ spaces. They are part of a community-based project that has supported them through the first wave of the pandemic, responding to their request for help to express and explore their gender and sexual diversity while being confined at home, in homes, and neighborhoods that often did not respect their right to expression (Hough, 2020). Before the pandemic, these adults with IDD had already demanded support to address their diverse sexualities, as well as participate in activities that respected their rights ‘without the imposition of one sole sexuality’ (Castejón Dueñas et al., 2019). They also demanded ‘greater co-leadership’ and to be able to decide on those initiatives and activities concerning their lives.

As we have explained, we explore the experiences of a group of people with IDD in Madrid coping with the first wave of the COVID-19 pandemic (March–May 2020). Since 2018, these adults have been participating in the Diversxs program that started out pro bono, a meeting space twice a month for LGBT+ people with IDD, created by the feminist NGO Genera¹ in collaboration with the Spanish federation of people with IDD (*Plena Inclusión*). Genera is a feminist organization that provides sexual health counseling and that became aware of the lack of services for people with IDD. Both organizations launched a program not only for LGBT+ people with disabilities but also for their families and for professionals in the field. This program is created based on their experience and desire to participate in mainstream LGBT+ organizations, events, or even online dating apps, where they have been rejected due to their IDD.

Before the pandemic, these participants faced obstacles to their attendance in the Diversxs program, such as resistance and opposition from their families and professionals and the expense of paying for their therapeutic companion’s train tickets, among others. Once the pandemic hit Spain, this group started meeting online twice a month and also used a WhatsApp group to keep in contact with their peers. The Diversxs program reached a total of 50 participants, heterogeneous in regard to their abilities, ages, interests, identities, living situations, sexual orientation, and gender identity, among other factors. Some of the participants did not continue in the online program once the pandemic started, due either to a lack of support or the digital overload, whereas others were able to join the program precisely because it was online. In any case, the majority found this new format helpful in coping with their situations and better expressing their needs.

The main meeting topics chosen by the participants were coping mechanisms for the pandemic, anxiety and pain due to isolation, fear of testing positive for COVID-19, family problems (disagreements, lack of privacy, and freedom to express themselves), restrictions set by their families to protect them from the virus, dating apps, LGBT+ resources, identity labels, and the celebration of Pride. Other topics not exclusive to the period of confinement included sexism, dating, toxic/healthy relationships, conflict resolution, sexually transmitted infections, intersectionality, cultural representations of LGBT+ people, conflicts within feminism, discrimination within the LGBT+ community, and overprotection of people with intellectual disabilities.

Method

The research that follows is an instrumental case study (León and Montero, 2015). This is due to the difficulty faced by the participants when they tried to engage in an online questionnaire from a

Table 1. Focus group discussion questions posed to the participants.

How was your experience with the confinement? Were you able to express yourself freely about your sexuality?

Were you able to be in contact with your friends who support your sexuality and gender identity?

How was your mood these days? Did it change? Was it caused by difficulties talking and expressing your sexuality at home?

Do you know any mutual help groups/NGOs that support LGBT+ people?

Have you suffered from COVID-19?

What is your experience within the LGBT+ community as a person with IDD? Have you been treated differently?

NGOs: nongovernmental organizations; IDD: intellectual and developmental disabilities.

study on the psychosocial impacts of the pandemic on LGBT+ people (Platero and López-Sáez, 2020). Therefore, we proposed another type of collection of perceptions through focus groups and started meetings with Genera and the Diversxs participants.

We complied with all ethical principles and informed all persons of the study's objectives and the confidentiality and anonymity of their responses. Likewise, we informed them of their freedom to respond and drop out when they considered it appropriate. Prior to the organization of the focus group, we consulted the Genera facilitators on the topics and the questions to make these accessible for all. The feedback we received corroborated this aspect.

After that, six participants (who already knew each other through Diversxs) accepted the informed consent and we conducted the meeting through Zoom. The meeting lasted 100 minutes, using mostly verbal communication. One participant was using both the chat function and oral messages, trying to avoid speaking while her parent was in the room, due to their lack of support for her diverse sexuality. Two facilitators from the NGO Genera accompanied us at all times, preparing in advance the questions that were posted, and during the session they often rephrased our questions and posted them again, using easier wording as well as inviting all participants to speak up.

We proposed six themes articulated through open-ended biographical-narrative and ethnographic questions (Charmaz, 2006; Spradley, 2016 [1979]; Wengraf, 2001), as shown in Table 1.

Our interest was to observe the themes that mattered, the meanings that certain experiences had for the participants, and the way in which the narratives of their experiences were constructed. Thus, we proceeded to a thematic content analysis (Gibson and Hugh-Jones, 2012: 139).

Once the meeting was over, we transcribed the recording and studied the main discourses through an inductive analysis. The aim was to find units of thematic meaning, coded and grouped by themes (Starks and Trinidad, 2007). Finally, we made inferences about the processes that could influence the participants to elaborate such a narrative.

Data on the characteristics of the sample of participants can be found in Table 2.

Results

The main diagnosis of the problems participants expressed was discrimination based on being people with IDD, which stops them from being able to freely explore their sexualities and gender identities. Precisely, this intersection of disability, gender, and sexuality provokes infantilization, excessive control, and invisibility, according to the participants. This discrimination becomes more evident once cohabitation in family homes intensified and their freedom to move and go out were

Table 2. Data of the participants of the focus group.

Participants	Sex	Age	Sexual orientation	Whom they lived with at the time of confinement
A	Male	41	Gay	Mother
M	Nonbinary	32	Left blank	Parents
C1	Male	32	Gay	Family
L	Female	37	I don't know	Family
D	Nonbinary	30	Bisexual	Shared a room with a partner in an apartment with other flatmates
C2	Queer	27	Polysexual, sapiosexual, polyamorous	Shared a room with a partner in an apartment with other flatmates

limited during the first wave of the pandemic (March–May 2020). In the following section, we will show some of the reflections based on the six questions posed. According to the Genera facilitators, the participation was similar to that of other sessions that the group usually holds without participating in research projects. In what follows, the participants' responses have been articulated based on the categories that they themselves were frequently expressing: confinement and pandemic, coping, the use of labels about their sexuality, fear of discrimination, the Diversxs online program, hookups, and their agency.

Confinement and COVID-19

Although none of the participants reported having COVID-19, all of them used the term 'roller coaster' of emotions to describe their experiences during the pandemic and ensuing confinement. C2 pointed out: 'I'm not doing badly with being confined at home for long periods of time. I'm used to it. It's more the fact that they are taking away from me something that is mine, my freedom'. Therefore, the difficulty is not being at home at all times but rather being unable to move around freely. C2 added that this roller coaster 'translates to somatizing a physical unease; I've had terrible insomnia'. Insomnia was repeatedly mentioned in this group. For C1, the intensity of so many video calls created stress and added anxiety. For A, 'at the beginning I had a few days where I was in shock; it seemed like some kind of joke'. Not being able to go out into the street was a problem, for example, in terms of being able to see your other partner, as pointed out by C2, who is polyamorous. In D's case, they had a difficult time because they were unable to help her partner C2: 'it hurts me to see her struggling and not be able to help her. To see that she's always confined . . . we live in a bedroom in a shared apartment, which we use only as much as necessary'. Everyone recognizes that the material conditions of the confinement were closely related to their ability to cope with stress.

Fear of discrimination

Due to some stories that appeared in the media showing harassment against LGBT+ individuals during the first wave, a fear of discrimination and aggression against LGBT+ people arose. For A: 'I'm not scared of going out onto the street. What scares me is making an involuntary gesture, or somehow outing myself as homosexual, that people can single me out or physically assault me'. This was a fear shared by other people in the group, revealing different layers of vulnerability as well as the need to use strategic passing to avoid aggressions. At the same time, they affirmed that,

due to their disability, they are treated differently from other LGBT+ people. They added that this program really helped them feel supported with respect to their sexuality and identity and coping with the fear of discrimination.

Coping

One method for coping with anxiety was to avoid watching too many news stories about the pandemic, and as C1 pointed out, participants turned to entertainment, such as watching TV series or going online, to overcome their anxiety. Several people pointed out that during the confinement, they had free time and were able to explore their sexuality and identity, especially online; this further exploration and search for information was also reported by mainstream LGBT+ services, such as the helpline Línea Arco Iris (FELGTB, 2020). With regard to this exploration, M said,

It helped me in the sense of being able to see that I'm not the only person who feels this way, and above all, to be able to visualize what's happening to me [. . .] When I was little, my best friend asked me if I felt like a man or a woman. And still to this day, this question shakes me up; I don't know how to define myself. It seems like society excludes you and you have to fit into a mold.

Labels

While the participants agree on the importance of using labels to name sexuality, there is no consensus on the use of such labels. For C2, labels are important and help them understand the world, whereas A confirms: 'The label bothers me. I already have enough labels, as someone with autism and Asperger's . . . without people putting me into another box'. At the same time, M points out that she only agrees with using them if she 'puts the label on myself'. On the contrary, the participants pointed out that there is a great lack of awareness around disability within the LGBT+ community, to the effect that there are some people who confuse having Asperger Syndrome with being bipolar, as A signaled. This lack of proper information and awareness was highlighted as a stigmatizing problem.

The advantages of an online program

Offering this support program online made participation possible for people who could not travel physically to the meetings, or who did not have family support to attend said meetings. It also enabled people who had trouble expressing themselves orally in on-site meetings to express themselves better remotely, typing in the chats, for example.

Hookups

In addition to friendships from the program, participants also looked for other places where they could relate to their peers, such as hookup apps. Three of them expressed more frequent use of the hookup apps during the time of confinement. They encountered significant obstacles on these apps, above all ones related to beauty standards and a rejection of people with disabilities. L pointed out that she felt discriminated against because of her disability and for being a woman who is 'a bit masculine'. A said that he does not know many of the terms used on these apps and related:

I go into the chat and a guy asks me about fetishes and sends me photos of his genitals, right off the bat, and I freeze up. He asks me to send him photos, but the thing is, I had never asked him for any. If I had known, I wouldn't have gone on the app, because that isn't what I was hoping for [. . .] I'm looking to get to know someone, but not to be pressured to send nude photos.

On these apps with photos, it is difficult to pass the filter when others see a photo of someone with a disability, and if the disability is not visible in the photos, violent situations can occur when the time comes to meet in person: 'Some people feel like you've tricked them', said M, implying the need to 'come-out' about their disabilities. Other participants, like C1, reported being able to use WhatsApp to hook up and sext. According to C2, 'there is both an endo-discrimination and an intersectional discrimination', concepts that they had already addressed during a training session in Diversxs, upon their request.

Agency

After the first wave of the pandemic, this group made public video appearances and were interviewed in major newspapers to discuss their unique experiences. Furthermore, some participated in a later campaign to denounce having been sterilized without their consent.

Discussion and conclusion

Understanding the situations that LGBT+ people with disabilities go through during this pandemic context provides important clues for social and health intervention. LGBT+ persons with IDD are exposed not only to the consequences arising from COVID-19 but also an exacerbation of preexisting risk factors. Before the pandemic, they were subjected to persistent prejudice and discrimination in many areas of their daily lives, restricting their right to openly live their sexuality and gender identities, with a lesser degree of freedom than their peers without disabilities have.

This article has proposed a research approach to the risks related to being LGBT+ and having IDD. The following themes have emerged from such an approach: (1) increased control and condescension while living in intensive cohabitation with family members and having their social contacts restricted, which set concrete barriers for their sexual rights; (2) the fear of discrimination during the pandemic, due to the news on bullying against LGBT+ people during this period; (3) the impact of the COVID-19 measures and confinement on their health, with high levels of anxiety, stress, and insomnia, among other symptoms; (4) the development of strategies to cope with the anxiety related to the COVID-19 pandemic; (5) the positive impact of online support programs on sexuality, highlighting that peer support groups helped them to gain agency over their lives; (6) the opportunity to further reflect upon their identities during their increased free time; and (7) critical discussions of the use of labels about their sexuality and disability.

Diversxs can be considered an example of best practices, a program that is responding to a concrete demand made by a very vulnerable group during a unique moment of crisis, in areas of their lives that are often neglected. Thanks to this program, participants formed relationships that helped them cope with feelings of isolation, anxiety, sleep problems, and stress, while offering them training and access to adapted information, as well as helping them explore their sexuality and gender identity.

Offering an online program was a special adaptation for this group, helping those who face significant barriers (being in the closet, lacking support to attend events, and having emotional barriers to face-to-face participation, among others). This type of online service has proved to be relevant not only during moments of crisis (López-Peláez et al., 2020) but also in everyday life.

Nonetheless, some participants also found it difficult to be online for several services, showing symptoms of screen fatigue.

Finally, the severe impacts of COVID-19 on certain population groups, such as the one we have studied, may help to bring into focus mechanisms to avoid social isolation and disparities in the service delivery, which is often offered by NGOs and community-based initiatives.

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Note

1. NGO Asociación Genera: Red de Mujeres Feministas (Genera, from this point forward).

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